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OLDER PEOPLE´S VIEWS RELATED TO THEIR END OF LIFE: WILL-TO-LIVE, WELLBEING AND FUNCTIONING

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OLDER PEOPLE´S VIEWS RELATED TO THEIR END OF LIFE:

WILL-TO-LIVE, WELLBEING AND FUNCTIONING

Helena Karppinen

ACADEMIC DISSERTATION

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Virta venhettä vie.
Mihin päättyvi tie?
Lyö kuohut purren puuta ja talkaa.
Mikä ihminen on?
Virvaliekki levoton.
Jo hiekka heljä riiteleepi jalkaa.
Yksi syntyy riemuun ja toinen murheeseen
ja kullakin on kellonsa pohjass' sydämen;
kun se seisahtaa, niin kuolon aika alkaa.
Virta venhettä vie.

Eino Leino (1901)

CONTENTS

LIST OF ORIGINAL PUBLICATIONS

The thesis is based on the following original publications, which are referred to in the text by Roman numerals I–IV. Some additional unpublished data are also presented.

I Karppinen H, Laakkonen ML, Strandberg TE, Tilvis RS, Pitkälä KH. Will-to-live and survival in a 10-year follow-up among older people. Age Ageing 2012; 41: 789-794.

II Karppinen H, Laakkonen ML, Strandberg TE, Huohvanainen EA, Pitkälä KH. Do you want to live to be 100? Answers from older people. Age Ageing 2016; 45: 543–549.

III Karppinen H, Pitkälä KH, Kautiainen H, Tilvis RS, Valvanne J, Yoder K, Strandberg TE. Changes in disability, self-rated health, comorbidities and psychological wellbeing in community-dwelling 75-95-year-old cohorts over two decades in Helsinki. Scand J Prim Health Care 2017; 35: 279-285.

IV Karppinen H, Laakkonen ML, Strandberg TE, Tilvis RS, Pitkälä KH. Living wills and end-of-life care of older people suffering from cardiovascular diseases: A ten-year follow-up. Eur Geriatr Med 2014; 5: 31-34.

ABBREVIATIONS

AADL	Advanced activities of daily living
ACP	Advance care planning
AD	Advance directive
ADL	Activities of daily living
BADL	Basic activities of daily living
DEBATE	Drugs and evidence-based medicine in the elderly (Cardiovascular prevention trial in Helsinki 2000-)
EOL	End of life
GEE	Generalized-estimating-equation (models)
IADL	Instrumental activities of daily living
LW	Living will
MMSE	Mini-Mental State Examination
PSDA	Patient Self-Determination Act (USA in 1990)
PWB	Psychological wellbeing
QOL	Quality of life
SD	Standard deviation
SMR	Standardized mortality ratio
SRH	Self-rated health
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (USA in the 1990s)
SWB	Subjective wellbeing
WTL	Will-to-live

DEFINITIONS

Advance care planning (ACP)	An ongoing process of making plans about an individual´s own future care. It provides the guidelines for decision-making when a person is no more capable of either making or communicating health-care choices. It may result in an advance directive.
Advance directive (AD)	A legal description of a person´s preferences for end of life.
Disability	Describes the limitation of functioning, caused by impairments or health-related environmental factors (WHO 2001).
Dying process	The time preceding death when dying becomes obvious.
End-of-life care	The care provided to a person whose illness is progressive and incurable and who has a short life expectancy, often days/weeks. In this thesis the period may be also months.
Impairment	Problem in body function or body structure (WHO 2001).
Living will (LW)	A common form of advance directive, where a person may also express detailed preferences to accept or forgo certain medical treatments. An oral LW is also valid.
The oldest-old	≥ 85-year-olds (Christensen et al. 2009).
Power of attorney	A legal document allowing one person to act as the agent of another, in case the person is not able to express the preferences himself/herself. Is regarded as a type of AD. In Finland, it has to be certified by authorities to be valid.
Psychological wellbeing (PWB)	A multidimensional concept of overall wellbeing. The PWB scale covers items about life satisfaction, feeling useful, plans for the future, zest for life, feeling depressed and suffering from loneliness.
Self-rated health (SRH)	A simple, validated and widely-used measure of health status on a four- or five-point scale. How do you perceive your health (considering your age)?
Will-to-live (WTL)	The degree of commitment to life, comprising cognitive, emotional, socio-environmental and personality aspects (Carmel 2015).

ABSTRACT

The aim of this study was to explore older people's wishes concerning their length of life, self-perceptions of their health, wellbeing and functioning, and lastly whether their documented living wills (LWs) are associated with care at the end of life.

The study was based on random samples of 75–96-year-old community-dwelling people in Helsinki (HEVA [the Helsinki Aging Study 1989, 1999 and 2009] and DEBATE [Drugs and Evidence-BAsed medicine in The Elderly 2000–2010]). In the DEBATE study the association between baseline will-to-live (WTL) and survival in the next ten years was analysed in a follow-up study of 283 participants (Study I). A wish to live up to 100 years, with reasons for this wish was explored in a cross-sectional study (Study II) concerning 1405 participants in the HEVA 2009 study. Changes in self-rated health (SRH), psychological wellbeing (PWB) and disability were rated, comparing cohorts in 1989, 1999 and 2009 (Study III, with 4898 participants). The association between baseline LWs and end-of-life care of 207 deceased DEBATE participants with cardiovascular disease (Study IV) was evaluated in a ten-year follow-up study.

A long WTL was more common in males, in younger people, and in those with good SRH. In a ten-year follow-up study, baseline WTL was a strong predictor of survival irrespective of age, gender and comorbidities (Study I). In Study II, 33% of the respondents were willing to become centenarians, some of them conditionally if functioning remained sufficient. A wish not to live extremely long was associated with fear of the future, negative attitudes and anticipation of diseases or disabilities. When comparing age cohorts over 20 years (Study III), SRH and PWB improved from 1989 to 2009, but levelling-off of previously detected improvements in physical functioning were worrisome. Living wills (Study IV) did not seem to affect the intensity of received care at the close of life. However, death occurred more often at home among those who had completed a LW at baseline, compared with those without a prior LW (17% vs. 6%).

Even though self-perceptions have been regarded as increasingly important, studies on WTL among older people have been scarce. Treatment options and specific health conditions were not in the scope of the present study, but instead, the results emphasize the importance of listening to older people themselves when planning their treatment plans and when developing future preventive and rehabilitative measures to support their WTL, quality of life, and functioning. The results of the present work suggest that increasing psychological wellbeing and care more congruent with patient preferences is possible. However, levelling-off of improving physical functioning among older people and the oldest-old is a study result that may demand more resources in social and health services than previously predicted. Discussions about preferences, living wills and their documentation in health files is suggested to take place early in primary care, even before severe diseases or disabilities.

TIIVISTELMÄ

Ikääntyneiden toiveet ja itsearviot ovat tämän tutkimuksen perusta. Väitöskirjassa selvitetään elämänhalua ja sen yhteyttä elinaikaan. Omaa arviota terveydestä, voinnista ja toimintakyvystä sekä niiden muutoksia ajassa tarkastellaan eri ikäisillä vanhuksilla. Lisäksi tutkitaan hoitotahdon yhteyttä elämän loppuvaiheeseen.

Tutkittavat olivat Helsingin vanhustutkimuksen (HEVA 1989, 1999 ja 2009) tai sydän- tai verisuonisairaiden vanhusten näyttöön perustuvan lääkehoidon interventiotutkimus DEBATEn (2000-2010) helsinkiläisiä kotona asuvia 75-96 -vuotiaita. DEBATE-seurantatutkimuksessa arvioitiin tutkittavien ilmoittaman elämänhalun (will-to-live, WTL) (tutkimus I, n=283) yhteyttä elinaikaan. HEVAn osallistujat (2009, n=1405) kertoivat halustaan elää 100-vuotiaaksi sekä perusteluja toiveelleen poikkileikkaustutkimuksessa II. Elämänhalun kartoituksen jälkeen tarkasteltiin vanhusten itse arvioitua terveydentilaa, psyykkistä hyvinvointia ja toiminnanvajeita sekä näiden muutoksia vastaavan ikäisissä kohorteissa kahdenkymmenen vuoden aikana vuosina 1989, 1999 ja 2009 (tutkimus III, n=4898). Viimeiseksi etsittiin yhteyksiä aiemman hoitotahdon ja elämän loppuvaiheen hoidon välillä DEBATE-aineiston kuolleiden osalta kymmenen vuoden seurantatutkimuksessa (tutkimus IV, n=207).

Pitkää loppuelämää (WTL) toivoivat tavallisimmin miehet, nuoremmat vastaajat sekä terveytensä hyväksi kokeneet. Elämänhalu vuosina osoittautui vahvaksi itsenäiseksi elinajan ennustajaksi vielä silloinkin, kun ikä, sukupuoli ja liitännäissairaudet vakioitiin (tutkimus I). Joka kolmas (33%) tutkimuksen II vastaajista toivoi elävänsä 100-vuotiaaksi - usein sillä ehdolla, että toimintakyky on riittävä. Toiveeseen kuolla ennen satavuotispäivää liittyi tulevaisuuden pelkoa, kielteistä asennetta ja oletusarvoinen huono toimintakyky tai sairaudet. Verrattaessa ikääntyneitä kohortteja kymmenen vuoden välein todettiin fyysisen toimintakyvyn kohentumisen pysähtyneen vuoden 1999 jälkeen, vaikka tyytyväisyys kasvoi 1989-2009: useammat kokivat terveytensä hyväksi, ja myös psyykkinen hyvinvointi oli parempi (tutkimus III). Tutkittavien aiemmin tekemällä hoitotahdolla ei näyttänyt olevan vaikutusta elämän loppuvaiheen hoidon intensiteettiin (tutkimus IV). Hoitotahdon tehneet kuitenkin kuolivat useammin kotona kuin ne, joilla hoitotahtoa ei ollut (17% vs. 6%).

Ikäihmisten elämänhalua ei ole aiemmin juurikaan tutkittu, vaikka itsearviointeja pidetään yhä tärkeämpinä. Yksittäinen tauti tai hoito ei ole tämän väitöstutkimuksen ydin. Sen sijaan tulokset rohkaisevat kysymään, kuulemaan ja huomioimaan ikääntyneen omia toiveita ja arviota hoito- ja kuntoutussuunnitelmaa tehtäessä. Omia arvioita tarvitaan myös yhteiskunnassa, kun suunnitellaan ikääntyneiden elämänhalua, elämänlaatua ja toimintakykyä parantavia toimia. Tulokset puoltavat ajatusta, että hyvinvoinnin paraneminen ja oman toiveen mukainen hoito on mahdollista. Löydökset viittaavat myös siihen, että tulevien vuosikymmenien ikääntyneet tarvitsevat arvioitua enemmän fyysistä apua. On suositeltavaa keskustella toiveista ja hoitotahdosta jo ennen vakavia sairauksia tai toiminnanvajeita ja kirjata keskustelut sairauskertomukseen.

1 INTRODUCTION

Heterogeneity increases with age. This applies to bodily functions, appearance, preferences and personal goals as well. No medical school provides students with an ability to know the thoughts of another, unless they are asked about them. Self-evident questions may yield a wide range of answers. A person´s will-to-live (WTL) is a concept that is familiar to care providers and lay people. It is easily accepted to be something that exists, yet, it has not been thoroughly studied (Damron Rodriguez & Carmel 2014).

Tomorrow will always be somewhat different from today. In 2016 the median age of female decedents in Finland was 85 years and it was 77 years in males. A rapidly increasing number of older people and the oldest-old (≥ 85 years) continue their lives in communities as health-care customers and increasingly also as care providers to others. Family members provide approximately 50% of care among the oldest-old in Nordic countries, which is lower than in Europe as a whole (80%), but which is expected to rise (Ronning et al. 2009). We need to find profitable ways to improve quality in the health-care system for all older people. Self-perceptions and patient preferences could be useful, and if so, they should be used more in practice. However, the data suggests that the relationship between objective and subjective measures of health is not as highly correlated at very advanced ages than in the younger old (Ferraro 1980, Lima-Costa et al. 2012, Ferraro & Wilkinson 2015). Hence, it may be valuable to investigate the thoughts of the oldest-old themselves, and follow their futures to extremely long lives.

Even though many older people prefer not to live up to extremely old ages, many of them will survive. Predicting future scenarios is difficult in terms of functioning. The current research includes a search for time trends, especially among those older people who will be the most active and who will mostly need primary-care services in outpatient clinics. Here the aim is to retrieve ample information from self-assessments to better anticipate future demand for services.

A document with preferences for care at the close of life represents a person´s commitment to the greatest extent. Traditionally, such existential issues have been mainly put aside by health-care professionals as being beyond their domain of expertise (Chochinov 2005). A greying society and lively public discussions about end-of-life (EOL) care, palliative care and euthanasia make us professionals ask if the contents of living wills (LWs) are known and if they are followed in reality. The trajectory from independency to dependency and death is a matter of interest not only to an individual, but also to health-care services and society in general.

The WHO launched the *international classification of functioning* (ICF), a framework for diagnostic and rehabilitation purposes in 2001 (WHO 2001). This publication stresses the importance of participation. Involvement and participation in decision-making is a sign of dignity in connection with EOL. If all aspects are to be assessed, the modern way to do this is to include assessments of physical, psychological, social, cognitive and existential functioning. Especially when older people are concerned, a thesis concerning wellbeing of this growing proportion of the population needs to include domains of good death – a death that better accommodates the preferences of older people themselves.

In this thesis, the points of interest are subjective perceptions. This dissertation concerns perceptions, preferences and self-assessments of functioning and wellbeing among older people and explores the reality in relation to their wishes.

2 REVIEW OF THE LITERATURE

2.1 OVERVIEW OF THE LITERATURE SEARCH

The inclusion criteria for considering studies for this literature review were originally based on the PICO framework (Population, Intervention, Comparison and Outcome), as follows: older people or centenarians (Population), good self-rated/perceived/subjective health or strong will-to-live (Intervention group), poor self-rated/perceived/subjective health or wish to die (Comparison), and future survival or future functioning (Outcome). Prospective, controlled or cohort studies were sought in PubMed, CINAHL and PsycINFO. However, data on the oldest-old were scarce concerning will-to-live, and too ample concerning self-rated health. Therefore, the references of identified articles and reviews were checked for relevance.

2.2 OLDER PEOPLE'S WISHES AND THOUGHTS CONCERNING THEIR LENGTH OF LIFE

2.2.1 Will-to-live

Concept of will-to-live

A strive for life is regarded as an instinct (Freud 1920, Lawton et al. 1999, Carmel 2017). In addition to this instinctual level, *will-to-live* (WTL) comprises emotional, motivational and cognitive components. WTL indicates the degree of commitment to life and desire to continue living and is also affected by social, environmental and personality aspects (Carmel et al. 2013, Carmel et al. 2016, Carmel 2017, Palgi 2017). Close but still distinguished concepts connected with WTL are *valuation of life,* and *subjective life expectancy* (Lawton et al. 1999, Mirowsky 1999, Lawton et al. 2001). Subjective life expectancy often corresponds well with actuarial estimates of survival. It is an estimation of the length of one's own life, with a rational base, such as judging one´s own possibilities to achieve longevity according to one's parents´ length of life (Mirowsky 1999, Perozek 2008, van Solinge & Henkens 2010). Commitment to life and motivation to live distinguishes the concept of WTL clearly from these other two concepts, as well as from *self-rated health* (SRH) (Jylhä 2009). WTL has been studied for only two decades, possibly because it has been assumed to be too obvious to be studied (Lawton et al. 1999).

Assessing will-to-live

During earlier decades a desire to continue living has been explored in ways other than measuring WTL. Sometimes WTL has been inquired in several hypothetical health scenarios, and together with distressing symptoms. Such studies have been conducted mainly among terminally ill cancer or HIV patients. The measurements were usually carried out several times during hospital stays. WTL among patients with severe diseases seems to be highly unstable, and it keeps fluctuating daily. (Chochinov 1999, Carmel 2001, Chochinov 2005, Emlet et al. 2011.) Sackett & Torrance (1978) and Tsevat et al. (1999) used *time trade-off models*, where people had to evaluate the number of years in poor health that they desire to trade, in order to live a shorter period in good health. WTL or choices about time trade-off have been investigated by using Likert or visual analogue scales to rate either strength of WTL or some detailed aspects of it. There have been no validated measures to assess WTL among the oldest-old in clinical practice.

For research purposes, WTL has been explored thoroughly in a relatively old Israeli population. Recently the Israeli researchers built a *WTL scale* with five items inquiring about WTL, changes in WTL, its strength, and the level of WTL compared with that in people of the same age (Carmel 2017). The scale includes also lifespan: "In your current condition, would you want to continue living for many years?" Older people (75+) are well capable and willing to respond to such questions on a Likert scale of 0–5. In recent years, emerging data has suggested that this scale shows good reliability, as well as construct and concurrent validity among community-dwelling older people (75+) (Carmel 2001, Carmel 2017). Otherwise, research on WTL has been scarce.

Thus, little is known about the prevalence of high-level WTL among older people or the oldest-old; all humans are supposed to have at least a certain level of instinctual WTL. However, in a study by Lawton et al. in 1994, American older people (aged 70+) living in communities were asked to express *years of desired life*. In this selected sample of healthy and wealthy senior citizens, half of the participants wished to continue living for 6–20 years, and every third participant wished to live even beyond that (more than 21 years after the baseline). In that sample, less than one out of five wished to live less than five years, and only 3% of them had no desire to continue living at all (Lawton et al. 1999). A strong WTL among young and old patients was also seen in *time trade-off* studies. The general population and young healthy adults were willing to trade some of their lifespan for a shorter but healthy life, but surprisingly, many patients and older people showed a strong preference for quantity over quality of life (Sackett & Torrance 1978, Tsevat et al. 1999).

A*ssociations with will-to-live*

Higher WTL levels are associated with favourable aspects of life such as less physical illness or symptoms (Chochinov 1999, Chochinov 2005). Table 2:1 describes studies on WTL or similar concepts and their

associations. Carmel (2017) explored and analysed associations between WTL and common determinants of wellbeing. Life satisfaction, happiness, self-rated health, morale and self-rated ageing had positive associations, and there were also inverse associations with depression and loneliness among older people (75+). Furthermore, WTL seems to predict depressive symptoms, not vice versa (Carmel et al. 2018).

Previous studies have shown that older age is associated with lower will-to-live (Carmel 2001, Carmel et al. 2013), probably as a result of age-related physical decline and pain (Chochinov 1999). There are also studies suggesting that negative perceptions or stereotypes of ageing and life can weaken older people's WTL. Many of these perceptions can be transmitted societally, resulting in a loss of self-dignity (Levy et al. 1999, Chochinov 2005, Marques et al. 2014, Bowen & Skirbekk 2016, Palgi 2017). In addition, among females, psycho-social indicators of wellbeing have more power than health indicators of wellbeing, compared with males (Carmel 2001). However, women experience life in a different way. Likewise, in many other aspects of life, there seem to be gender differences in WTL: older males report stronger WTL than older females (Carmel 2001, Carmel et al. 2007).

WTL is related to long-term survival (Carmel et al. 2007). However, despite a death-related decline in *life satisfaction*, WTL seems to remain unchanged even when death is nearing (Carmel et al. 2013). Researchers of WTL among terminally ill patients have reported high WTL at the end of life (Chochinov 1999). An interesting finding was made in Sinard´s analysis, where people seemed to be able to postpone their death for the opportunity to live into the twenty-first century, judging by the overrepresentation of deaths in January 2000, without any other plausible explanations (Sinard 2001). Carmel has previously reported that Israeli older people showed a strong positive association between WTL and fear of death (Carmel 2001).

Will-to-live versus wish to die

One may pose the question about wish to die and its association with WTL. Wish to die has been poorly explored, whereas suicidal ideation is known better. However, in clinical practice, i.e. in rehabilitation units, the phenomenon is identified: at some point, there is no progress in rehabilitation without a medical explanation, and later the patient will die (Askinazi 1997). There are ample data about increased mortality predicted by suicidal ideation or depression in community-dwelling older people (Dewey et al. 1993, Skoog et al. 1996, Raue et al. 2007). Interestingly, wish to die in the absence of other evidence of depression and regardless of disabilities or age, also seems to predict mortality in community samples (Macdonald & Dunn 1982, Raue et al. 2010).

Older people think of death more often than younger ones. Very old people may feel that life is not worth living, or they even have death wishes without any intention to commit suicide. Among an 85-year-old Swedish sample of mentally healthy people, 4% of them reported having these thoughts. The proportion was

much larger, one out of four, among the oldest-old with mental disease (Skoog et al. 1996), whereas in the Netherlands (*Longitudinal Aging Study Amsterdam*), one out of five older people (58–98 years) acknowledged their wish to die (Rurup et al. 2011). Both wish to die and loss of WTL are entities distinct from depression, grief, or sadness (Askinazi 1997, Rurup et al. 2011). If the loss of WTL is due to negative old-age expectations, older people with a shorter subjective life expectancy may invest less in their health, resulting in avoidance of health-care services, exercise and other forms of beneficial health behaviour (Sarkisian et al. 2002, Bowen & Skirbekk 2016). Whether there is an association between wish to die and loss of WTL remains unknown. In this study, the main focus was chosen to be on positive resources in humans.

Table 2:1. Studies on associations with and concepts parallel to will-to-live

Study Country (survey year)	Setting, design Study concept if other than WTL	Participants	age	phys imitations, diseases	life-satisfaction	wellbeing/ happiness	self-esteem	depression/ anxiety	proximity to death	other associates
Lawton et al. 1999 USA (1994)	selected community-samples, structured interview "Years of desired life"	n=600 70+ y, mean age 77 y	↓	↓						education ↔
Chochinov 1999 Canada (1993-95)	palliative care (cancer patients)	n=168 31-89 y		↓		↑		↓		
Tsevat et al. 1999 USA (1996)	questionnaire and in-depth interviews of HIV-infected	n=51 24-67 y								love for one´s children ↑ spirituality ↑
Carmel 2001, Carmel et al. 2013 Israel (1994-)	population-based, structured interview at home 7.5-year follow-up	n=987 (♀ 47%), 70-101 y, mean age 78 y	↓	↓ ♂	↑ ♀		↑ ↑ ↑		↔	fear of death ↑↑ education ↔
Raue et al. 2010 USA (1999)	community-based 5-year follow-up "Wish to die"	n=1202 60+ y								predicts mortality
Rurup et al. 2011 Netherlands (2005)	community-based interviews "Wish to die"	n=1794 58-98 y						↑		mastery↓ financial problems↑ loneliness↑ small network↑ incontinence↑ being divorced↑ having a speech impediment↑
Huohvanainen et al. 2012 Finland (2007)	Community-dwelling, postal survey "Wish to live to 100?"	n=712 (♀ 0) 72-88 y	≤78 ↔ >78 ↑	≤78↓ >78 ↔		>78 ↑				marital status↔ regular exercise↔ PWB↔ ≤78 good financial status↓ >78 living will↓
Bowen & Skirbekk 2016 USA (2009)	interviews "Preferred life expectancy"	n=1631 (♀ 50%) 18-64 y mean age 42 y	↔							negative old-age expectations↓ positive old-age expectations↑
Palgi 2017 Israel (2014)		n=339 50-90 y							↑	post-traumatic-stress-symptoms ↑/↔ if expected lifespan was very long↑, If short↔
Carmel 2017, Carmel et al. 2018, Shrira et al. 2018 Israel (2010-)	community-based longitudinal, 1-2y follow-up, interview at home	n=870-1019 (♀ 45%) 75+ y mean age 80 y	↓		↑			↓		SRH↑ morale↑ self-rated ageing↑ loneliness ↓ WTL predicts depressive symptoms, not vice versa. SRH predicts WTL and depressive symptoms. Reciprocal relationship between subjective and objective successful ageing.

2.2.2 To live or not to live extremely long

How long do people want to live? What is a good life or *successful ageing*? The concept of successful ageing has gained a lot of attention from policy makers and scholars (Rowe & Kahn 1998, Jopp et al. 2015). Key factors for good old age have been explored in theoretical models and demographics of the oldest-old. The theoretical models of successful ageing will not be discussed here in detail. Instead, the focus will be on opinions of older lay persons themselves: how do they perceive their future years, or what might be the motivational aspects in their lives? Future expectations may be better predictors of life than orientation in the past (Ferraro & Wilkinson 2015).

The future will be different from the past in terms of population. Almost every third European will be older than 65 in 2060. At that time, one in eight is expected to be 80+ in Europe; one in ten in Finland (10.3%) (Eurostat 2011). However, older people may have negative attitudes towards ageing, which has an unconscious effect on the wish to live long (Levy et al. 1999, Marques et al. 2014, Bowen & Skirbekk 2016, Kalfoss 2016). In addition to attitudes, expectations of old age are related to how long people want to live (Bowen & Skirbekk 2016).

The scope of lay people seems to be wider than the traditional concept of successful ageing proposed by Rowe and Kahn (1998): instead of reporting health and/or engagement issues only, lay people point out additional personal aspects such as social relations and wellbeing, plans and wishes, attitudes, beliefs and life management (Jopp et al. 2015, Huijg et al. 2017). Home-care clients named some personal resources that helped them stay at home in Finland: sense of control of one´s life, and determination to stay active (Eloranta et al. 2008). Family plays an important role in ageing – but not in a similar way among all nationalities, which has been noticed in comparison of Indian, Malay and Chinese populations in Singapore (Feng & Straughan 2017). However, most older people can name role models for ageing in their own families, leading to more positive views on ageing (Jopp et al. 2017). Younger people may often consider loneliness as a significant reason not to live long, meaning that living alone and possibly socially isolated would be undesirable (Deeming 2013).

Some researchers have investigated older people´s preferred lifespan, or their willingness to live to extremely old ages. If young adults or the middle-aged are asked, pessimistic expectations of life in old age often undermine a willingness to live up to and beyond their probable average life expectancy (Bowen & Skirbekk 2016). In a study conducted in the USA, none of the 70–97-year-olds investigated (n = 109) wished to live up to 100 (Cicirelli 2006). In *Helsinki businessman study*, one in three men aged 72–88 years (mean 79 years) wished to become centenarians (Huohvanainen et al. 2012). Recent attitudes among Portuguese older adults

have been even more positive: over half of the participants (54.7%, aged 60–90 years) wished to live up to 100 years (Ribeiro et al. 2018).

Increasing numbers of people survive to 100 years. Some studies among centenarians and near-centenarians have explored the thoughts of very old people. The oldest-old in both Cambridge (95–101 years) and participants of the *Fordham Centenarian Study* in New York (95–107 years) had a friendly relationship with death. They were not worried about death itself but concerned about the dying process and especially the family members who would be left behind. Quality of life, not being a nuisance, and a peaceful painless death was an ideal. As one of them put it: "I am ready to go – but not today or tomorrow." They usually wished to avoid hospitals. (Fleming et al. 2016, Jopp et al. 2016.)

Qualitative research reveals challenges in life experienced by centenarians. Functioning arises as the first challenge, with deteriorating senses and mobility. Psychological and social aspects of life come next. Surprisingly, loneliness or low-level social activity does not play an important role. Instead, centenarians are more worried about their nearest ones. (Jopp et al. 2016.)

2.3 SELF-PERCEPTIONS OF HEALTH, WELLBEING AND FUNCTIONING AMONG OLDER PEOPLE

2.3.1 Self-rated health

Definition

Self-rated health is a widely-used tool to rate health status. It reflects the comprehensive picture of health as perceived by an individual. It is a way to evaluate the most meaningful dimensions of health for the individual him/herself (Jylhä 2006, Parker & Thorslund 2007). The first clear indication of its usefulness in large studies was reported in the *Canada Manitoba Longitudinal Study* as early as 1982 by Mossey and Shapiro. SRH was a better predictor of survival than objective health state or life satisfaction (Mossey & Shapiro 1982). Similar ratings had been used in research before that on a small scale (Jylhä 2006). Self-rating provides a simple, easy, and global way of capturing perceptions of health, highlighting the lay perspective. Previously research on health was built on data from medical records rather than from self-perceptions (Idler 1997).

Measurement is valid and predictive

The established way to measure SRH is by way of a question where people are asked to rate their present health status on a scale (4 or 5 levels) from excellent to poor (Jylhä 2006). In some surveys a person is asked to rate health in comparison with that in other people of the same age, or during the last fortnight etc., but generally the question has been kept simple: "*How would you rate your present health status*?". SRH has become a widely-used health indicator due to its reliability and prognostic validity among older people in both population-based samples and in patient groups. The consistency of study findings from around the world is imposing. (Lundberg & Manderbacka 1996, Idler 1997, Ferraro & Wilkinson 2015.)

In addition to its ease of administration, it is a strong predictor of mortality, especially in community-dwelling older people (Mossey & Shapiro 1982, Idler 1997, Leinonen 2001, Nybo et al. 2003, af Sillen et al. 2005, Parker & Thorslund 2007, Cesari et al. 2008, Ford et al. 2008, Jylhä 2009, Ferraro & Wilkinson 2015), and also among patient groups (Jylhä 2006). A gender difference seems to exist: men´s poor ratings are more predictive of mortality than are those of women (Idler 1997, Idler at al 2000, af Sillen et al. 2005), although in some large population-based studies the predictive value of SRH has been equal in both genders (Lima-Costa et al. 2012). In a 22-year follow-up study in Malmö, Sweden, poor SRH was also a predictor of morbidity even when adjusted for possible confounding variables (af Sillen et al. 2005).

Associations of SRH

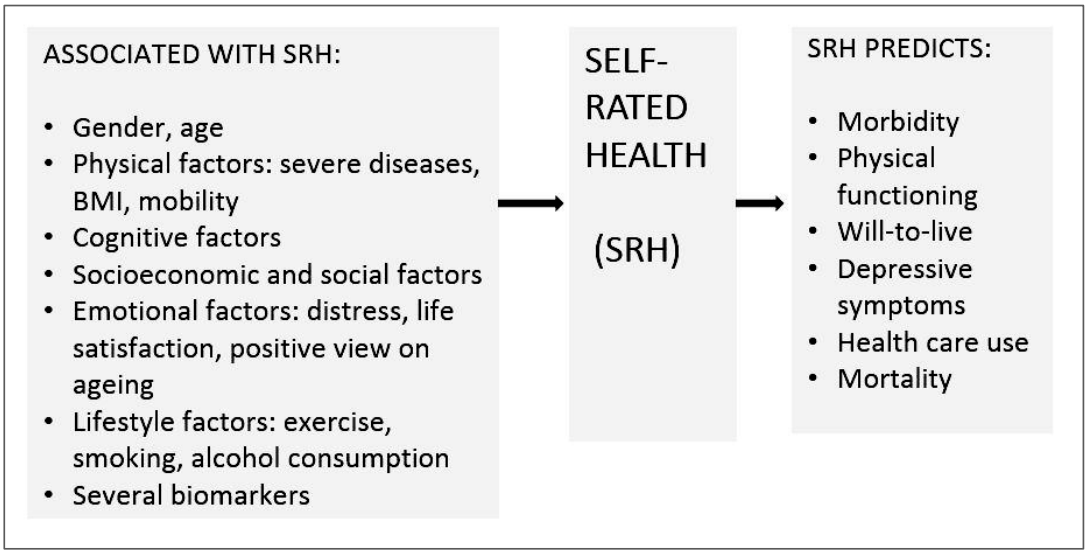
Associations of SRH show convincing evidence of its importance in health assessments (Figure 2:1). Although a self-assessed perception, it seems to have a *biological basis*: there is a strong relationship with many laboratory test results, which has been confirmed in large samples of older people in the USA. As regards haemoglobin and white blood cell count, in one study this association remained even after adjusting for several diseases, other biomarkers and demographic factors. (Jylhä 2006.)

Physical limitations, *disabilities* and *chronic conditions* are convincingly associated with SRH, at least among younger older people (Idler 1997, Damián et al. 1999, Leinonen et al. 2001, Damián et al. 2008). SRH is associated with *cognitive decline* (Leinonen et al. 2001), but association with *depressive feelings* or *socio-economic situation* seems to decrease with age. While younger adults perceive their health to be worse with depressive feelings, the oldest-old accept feelings of dejection as a part of their lives. However, especially among nursing-home residents the association of SRH with *social class* or *depression* is strong. (Damián et al. 2008.) In Spanish studies Damián reported the highest-level SRH among the subgroup of 85+ years of age (Damián et al. 1999). *Social contacts* and ability for *maximal work* among older women seem to be associated with SRH, unlike among men (Leinonen et al. 2001). Change in *physical exercise* moderates SRH as well (Leinonen et al. 2001). In younger-aged cohorts inverse associations with tobacco *smoking* and *alcohol*

consumption have been linked to SRH in some studies, and body mass index (*BMI*) among the oldest participants (Damián et al. 1999, af Sillen et al. 2005).

As reported earlier, SRH does not seem to decline remarkably with *age*. Some contradictory findings have been reported in Spain, where age was a main determinant of SRH (Damián et al. 1999). However, *positive views on ageing* were associated positively with SRH in a follow-up study (Hicks & Siedlecki 2017), and the association between SRH and age has also been reported to decrease (Doblhammer & Kytir 2001).

Figure 2:1. Associates and predictive value of self-rated health (SRH) (Modified from Idler 1997, Leinonen et al. 2001, Jylhä 2006 and Carmel 2018)



BMI = Body Mass Index

Self-rated health among older people

A large proportion of older people in western countries rate their health as "good" or "very good" (Table 2:2). Depending on the scale and how the variables are dichotomized, the prevalence rates of good SRH vary. Usually half of all participants report "fair" SRH, if it is an option (Doblhammer & Kytir 2001). Older people seem to judge their health in slightly different domains than younger adults. Researchers have reported surprisingly good ratings with increasing age. However, interpretation of the precise measure of SRH has to

be noted: older people report higher levels of optimism in connection with SRH compared with younger age groups, when a comparative measure as opposed to an absolute measure (SRH "compared with people of the same age" vs. "How would you rate your present health?") is used (Roberts 1999, Collerton et al. 2009).

Unlike persistence in old age, gender differences have been consistent. Older men rate their SRH better than women of the same age, regardless of differences in their comorbidities or survival. (Verbrugge 1985, Blaxter 1987, Verbrugge 1989, Idler 1997, Collerton et al. 2009.) Prominent gender differences diminish towards very old ages, although data concerning this age group are still scarce (Damián et al. 1999, Doblhammer & Kytir 2001).

Table 2:2. Prevalence of good or very good self-rated health among older people

Study, country (study year)	Participants, setting, design	good SRH, %	Comments
Dening et al. 1998 UK (1985)	n=2609 (♀ 68%), 75+, community-dwellers in GP practices, interview	67	"compared with others of the same age"
Damián et al. 1999 Spain (1994)	n=677 (♀ 62%), 65+ y, mean age 74.0 y, community-dwelling in Madrid, interview at home	50	poor SRH 23% > 85-y: highest SRH
Leinonen et al. 2001 Finland (1989)	n=382 (♀ n=263, 69%), all 75-year-olds in Jyväskylä	57	poor SRH 43%
Nybo et al. 2001 Denmark (1998)	n=1798 (♀ 1307, 73%), all 93-year-olds in Denmark, interview and assessments at home	56	poor SRH 11%, "compared with others of the same age"
Bootsma-van der Wiel et al. 2001 Netherlands (2000)	n=599 (♀ 397, 66%), 85 y, community-based	70	
Ford et al. 2008 Australia (1996)	♀ n=12 033, 70-75 y. population-based postal survey	72	poor SRH 28%
Damián et al. 2008 Spain (1998)	n=669 (♀ 50%), 65+ y, mean age 83.4 y, nursing-home residents in Madrid, interview + assessment by an MD	55	Most residents were independent, and cognition was intact
Collerton et al. 2009 UK (2006)	n=853 (♀ 530, 62%), 85 y, population-based (10% institutionalized, registered in GP offices), health assessment and recorded interview	78	poor SRH 22%, "compared with others of the same age"
Lima-Costa et al. 2012 Brazil (1997)	n=1322 (♀ 62%), 60-93 y, mean age 69 y (SD 6.9), population-based, interview and assessment	25	poor SRH 25%
Kalfoss 2016 Norway (2003)	n=482, 60+ y, mean age 76 y, population-based, postal survey + interview	83	
Fleming et al. 2016 UK (2006)	n=42 (♀ 88%), 95-101 y, population-based (community-dwelling 57%)	66	poor SRH 17%
Sapranaviciute-Zabazlajeva et al. 2018 Lithuania (2016)	♂ n=1793, mean age 69 y (range 55-82 y) ♀ n=2473 mean age 69 y (range 55-82 y) community-based random sample, postal survey	29 ♂ 23 ♀	poor SRH 9% poor SRH 12%

Intra-individual ratings seem to be relatively constant: In a Finnish study, older people were asked to rate their health several years apart. In most cases their answers remained the same. One out of five reported SRH to be worse than five years earlier, but an equal proportion of older people reported better SRH than before. If older people are asked about their health status, or change in their health, the responses are realistic: over time they have more chronic conditions and more impairments in functioning, but they still compare their health with that in other people of the same age, and report SRH as they did before. This was the case in the *Evergreen project* among all 75-year-olds in Jyväskylä, Finland. (Leinonen 2001.)

2.3.2 Psychological wellbeing (PWB)

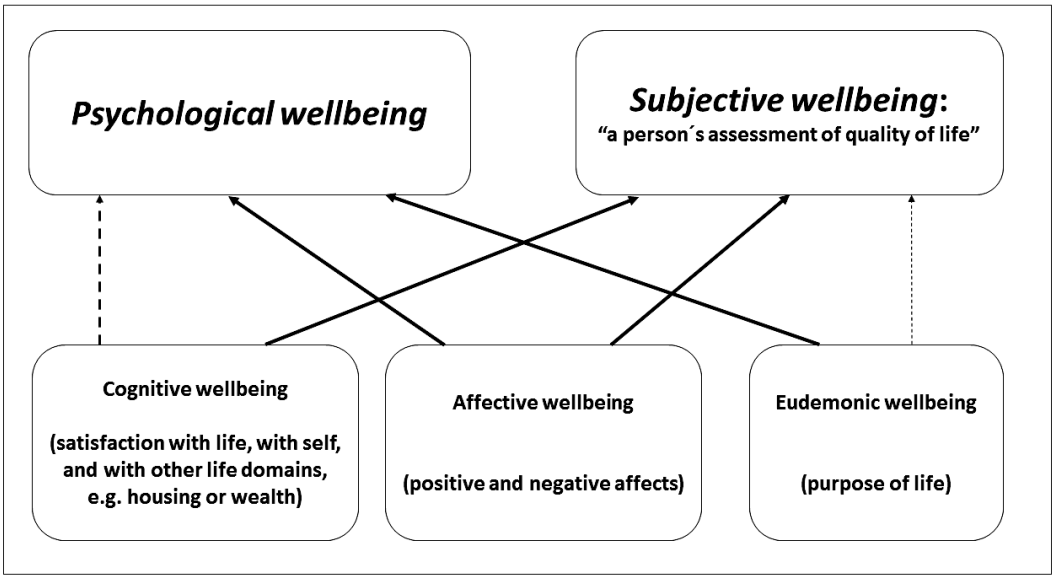
Conceptual framework of PWB

The question "What is a good life?" has been discussed by philosophers and writers since the times of Plato, Socrates, and Aristotle. They conveyed the idea that happiness originates in virtuous action, wisdom, and positive life circumstances (Deeming 2013). Since the 1970s there has been an emphasis to place value on self-rated rather than merely objective wellbeing. Wellbeing cannot be rated without a personal impression and experience of one´s own life. Even now there is no precise definition of PWB for research purposes. Various aspects of life have been included in the concept of PWB. Expressions of PWB can be divided into three domains: (1) *life satisfaction* in itself (evaluative or cognitive PWB), (2) *feelings* (hedonic PWB) and (3) *purpose of life* (eudemonic PWB). (Dolan & Metcalfe 2012, Deeming 2013, OECD 2013, Steptoe et al. 2015.)
The definition of a close relative of PWB, namely *subjective wellbeing* (SWB), in terms of Ed Diener, a renowned psychologist in this field, is that "subjective wellbeing is an umbrella term for the different valuations people make regarding their lives, the events happening to them, their bodies and minds, and the circumstances in which they live" (Diener et al. 2006). SWB has become more important during the last decade. Demand for knowledge about subjective evaluations and their relationship with socio-demographic variables is increasing. Data on SWB is applied in policy-making and planning of social services. Four important items are usually inquired about for SWB: (1) Overall life satisfaction at present, (2) Worthwhile things in life, (3) Happiness, and (4) Anxiousness (Deeming 2013). The distinction between PWB and SWB is

not clear, but it lies in the relative importance of the three domains mentioned above. Eudemonic wellbeing (e.g. meaning of life) is strongly built into PWB measures, whereas environmental and other life domains (e.g. income, occupation) are more pronounced in SWB. SWB has been suggested to be the person´s expression of *quality of life* (QOL). Figure 2:2 illustrates the relationships between these overlapping concepts.

Quality of life has been inquired about and studied in more detail than SWB and PWB. QOL and PWB are not synonymous. QOL is more affected by a person´s health status and environmental issues, whereas existential perspectives are more prominent in PWB (Steptoe et al. 2015). In 1998 the WHO established a definition of QOL: four important domains have to be considered and assessed: (1) physical, (2) psychological, (3) social relationships and (4) environment. The WHOQOL questionnaire consists of 100 items covering all these entities. A shorter questionnaire, WHOQOL-BREF, is a more practical tool for measuring QOL, including only 26 items from these four domains. (WHOQOL-BREF 1998.)

Figure 2:2. Overview of the related concepts psychological wellbeing and subjective wellbeing. The strength of the line illustrates the importance of the concept.



How to assess PWB?

The WHOQOL-BREF measure is often applied because of its validity and reliability among adults and older people, in population-based surveys and in different groups of patients. In particular, construct validity and test-retest reliability are good (WHOQOL Group 1998, Huusko et al. 2006). Of the three domains of PWB, hedonic feelings and mood may be self-assessed easily and quickly on request, but rating of evaluative or eudemonic wellbeing requires more pondering, and this domain is also poorly represented in the WHOQOL-BREF questionnaire. One applicable tool for rating PWB among older people consists of six simple inquiries about (1) life satisfaction, (2) feeling useful, (3) plans for the future, (4) zest for life, (5) depressed feelings, and (6) feelings of loneliness (Tilvis et al. 2000, Pitkälä et al. 2004). This tool is explained in detail below, in section 4.2.1. All three domains of PWB (evaluative, hedonic and eudemonic) are covered by these six inquiries. The resulting PWB score (poor, moderate, good) has a strong association with all four WHOQOL-BREF domains among older people, with the highest association to the psychological domain (Huusko et al. 2006). Its psychometric properties seem to be good as well: it has good test-retest reliability (Savikko et al. 2006) and significant prognostic validity as regards mortality (Pitkälä et al. 2004).

There are numerous other measures for PWB, QOL, SWB and their individual domains. *Life satisfaction* was among the first entities in subjective measurements. One of the first scales was the *Cantril ladder* where a person needs to choose 0–10 depending of the level of satisfaction in life, and there is a more complex questionnaire with five questions and a 5-level score for responses. (Pavot et al. 1991, OECD 2013.) Depressive feelings can be assessed, for example, with the Geriatric Depression Scale (Yesavage et al. 1983). Among older people one of the validated self-administered measures for QOL is CASP-19 (Hyde et al. 2003), items of which rate basic needs according to Maslow (control, autonomy, pleasure and self-realization) (Maslow 1948). In doing this, it may be applied for assessing most domains of PWB as well (Hyde et al. 2003).

There are more scales with good psychometric properties for some other dimensions of PWB. The *De Jong-Gierveld loneliness* scale consisted originally of 11 items in 1985, and refrains from mentioning the word loneliness. Its five positively and six negatively loaded items measured merely the severity of feelings of loneliness. (De Jong Gierveld & Van Tilburg 1999.) Later a refined version with three items on affective loneliness and three items on social aspects of loneliness was constructed (De Jong Gierveld & Van Tilburg 2006, De Jong Gierveld et al. 2016). *Life satisfaction* can be assessed with the SWLS (satisfaction with life scale) tool (Pavot et al. 1991), and happiness by rating the statement “I feel happy” on a Likert scale of 1–5 (Jopp & Rott 2006).

Psychological wellbeing among older people

Psychological wellbeing changes with age. Figure 2:3 below illustrates the life-course perspective, or a rough generalization, of some domains of PWB. Some large-scale studies have shown a U-shaped association between age and *life satisfaction* (Blanchflower & Oswald 2008, Deeming 2013, Steptoe et al. 2015). The oldest age groups (75+) present with significantly higher *life satisfaction* and *happiness* than younger adults (Deeming 2013), or at least the rate of decrease in satisfaction with life becomes slower (Carmel et al. 2013), whereas middle-aged and younger older people often report the lowest levels of PWB (Blanchflower & Oswald 2008). In a representative sample of 93-year-old Danish people in 1998, 74% of the participants were very satisfied with their lives (Nybo et al. 2001).

Resilience – an individual´s capacity to adapt – is often considered to be linked to very old ages. In the *Heidelberg Centenarian Study* (Jopp & Rott 2006) about 100 centenarians were interviewed about their perspectives on life. Overall, the results showed that they felt at least as *happy* as middle-aged and aged people, providing no indication that centenarians have lower wellbeing compared with younger people. Over 50% of the centenarians were as happy as before. A comparable survey among 95–106-year-olds in New York confirmed high resilience and life satisfaction among very old people. In addition to resilience among the oldest-old, the results may be biased because of selection: centenarian responders are always survivors, thus presenting more optimistic attitudes than are present in younger groups of older people. (Jopp & Rott 2006, Jopp et al. 2016.)

Loneliness is experienced by people of all ages and in all countries. In a longitudinal study (TamELSA) in Tampere, Finland, the highest percentage of lonely older people in 1989 was 55% in the group of 85–89-year-olds, whereas 26% of the younger retirees reported loneliness (Jylhä 2004). National differences in the prevalence of loneliness were remarkable in a large amount of data from the European Social Survey using a one-item direct measure of loneliness in 2006–2007. Loneliness increased towards older ages, and the lowest prevalence rates of loneliness among the oldest population were reported in Northern Europe (3–9% among the 60+ population; 6% in Finland). Southern European countries came second (10–15% among the 60+ population), and the largest proportion of older people suffering from loneliness was in Eastern European countries (19–34% among the 60+ population). Researchers explained the difference in terms of higher socioeconomic position and the availability of appropriate social welfare policies for those in need in Northern countries. (Yang & Victor 2011, De Jong Gierveld et al. 2016.) It should be noted that the feeling of loneliness is not stable in an individual; although loneliness increases with age, up to 25% of lonely older people do not feel lonely later on (Jylhä 2004, Dahlberg et al. 2015, De Jong Gierveld et al. 2016).

Gender differences are evident in many domains of PWB. In population samples of different ages, women seem to lead more *meaningful lives* than males (Deeming 2013). On the other hand, they more often report

anxiety and loneliness compared with men (Deeming 2013, Dahlberg et al. 2015, Carmel et al. 2017). Reduction in social contacts, as well as losses, disabilities and illnesses predispose males to loneliness, whereas problems in mobility predict loneliness among older females (Savikko et al. 2005, Dahlberg et al. 2015). After traumatic events, females present with more depressive symptoms (Carmel et al. 2017).

Psychological wellbeing is affected by many factors such as social relationships, roles in life, activities, valuation of life and even material conditions. Having *plans and wishes for the future* is strongly related to life satisfaction among older people (Hicks & Siedlecki 2017). Physical activity seems to improve PWB, along with increasing self-esteem, self-image and self-assessment of other aspects of health. Physical activity seems to be the health-behaviour factor showing persuasive evidence in improving most domains of PWB (Leinonen 2001).

Finally, the predictive value of wellbeing in relation to survival has been consistent; high-level wellbeing is protective (Tilvis et al. 2000, Pitkälä et al. 2004, Steptoe et al. 2015), as is an optimistic attitude, even in the oldest-old (Engberg et al. 2013). In Finland, Tilvis et al. explored various domains of PWB as predictors of survival: a feeling of being needed and useful showed the strongest association, but also plans for the future and absence of depressive feelings or loneliness were strongly associated with good survival in a five-year follow-up study. Social isolation in itself has not emerged as a risk factor, unlike suffering from loneliness, which is a powerful risk factor as regards mortality. Similarly, social inactivity seems to be associated with poor prognosis. Life satisfaction and zest for life played minor roles although they were predictors as well. (Tilvis et al. 2012.)

Figure 2:3. An overview of age-related levels in some domains of wellbeing and related concepts during the course of life. Not in scale

Domain of wellbeing Study	Approximate changes over life-course	comments
LIFE SATISFACTION Blanchflower & Oswald 2008, Steptoe 2015		Life satisfaction in Western countries Minimum at 47 y in both genders (50 y in Finland) Later-born American male cohorts show less satisfaction than before
		Life satisfaction in former Soviet Union and Eastern Europe
HAPPINESS Jopp & Rott 2006, Blanchflower & Oswald 2008, Deeming 2013		Most centenarians say that they are as happy as they were when middle-aged. 75+ are even happier than other adults. Minimum happiness in middle age (♀ 40y, ♂ 50 y).
LONELINESS Jylhä 2004, Yang & Victor 2011, Dahlberg et al. 2015, de Jong-Gierveld 2016		Younger old people feel the least, adolescents the most loneliness. The country in which one lives predicts reported loneliness more than age.
DEPRESSIVE FEELINGS Blanchflower & Oswald 2008		Maximum at 45–50 years
WELLBEING Bowen & Skirbekk 2016		No data on the oldest-old
SOCIAL CAPITAL Glaeser et al. 2002		

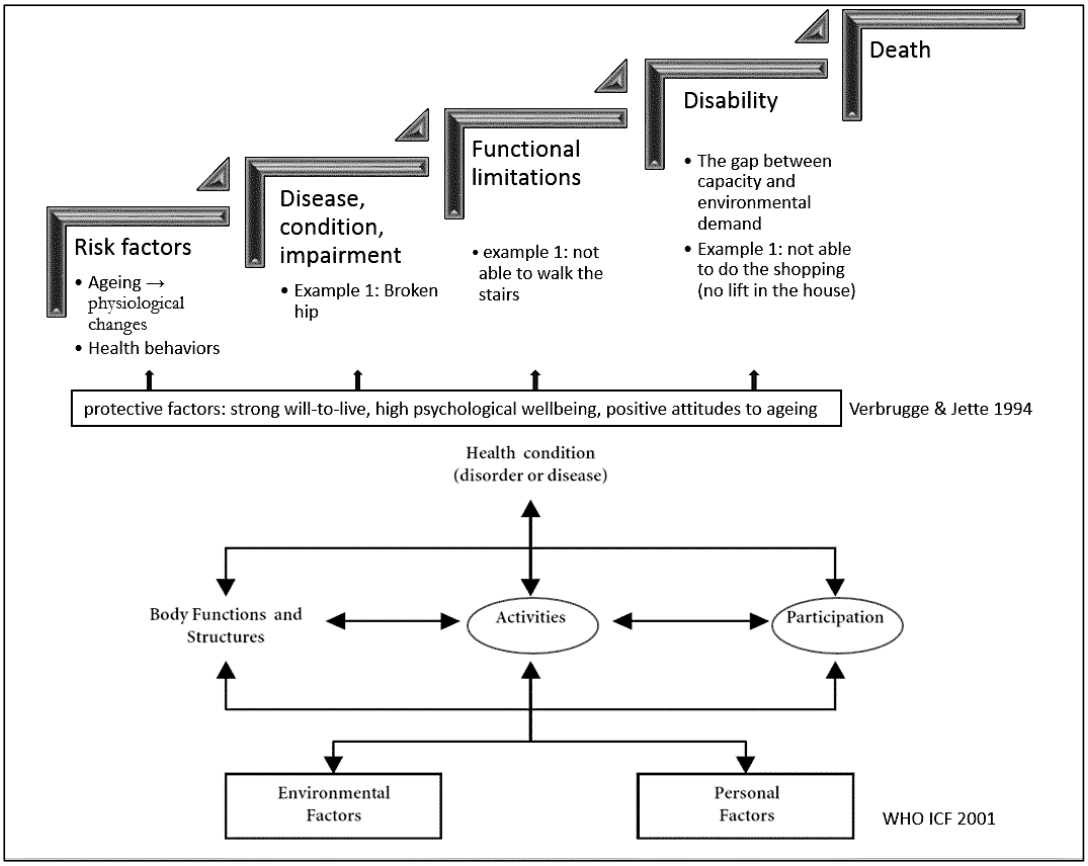
2.3.3 Physical functioning

Physical functioning plays a major role in assessing overall functioning. Numerous aspects of physical functioning can be categorized into three kinds of activities of daily living (ADL). Firstly, advanced ADL (AADL) comprises complex capabilities, e.g. participating in social events, giving parties or doing complex work. Secondly, instrumental ADL (IADL) describes the abilities required for household work, shopping, commuting, making telephone calls, or taking care of medication. Lastly, basic activities of daily living (BADL) reflect physical dimensions of daily tasks (eating, using the toilet, mobility, dressing, communication, grooming, ambulation, continence and bathing). (Kane et al. 2013.)

Ageing does not result in inevitable disabilities and dependency. The course of development of disabilities was described by Nagi in 1975 and modified by Verbrugge and Jette (Verbrugge & Jette 1994) (Figure 2:4). The WHO ICF (International Classification of Functioning) framework is an extended model of these (WHO 2001). Certain diseases and their pathology or ageing itself may cause some inconvenience and physiological changes (Nagi 1975). These may in turn cause impairments, e.g. impairments in hearing, loss of vision, or dyspnoea caused by cardiac failure. These impairments may lead to limitations in functioning and further to disabilities in a person´s daily life. Disability means that a person is unable to perform certain tasks. However, in different environments or social surroundings the same impairments or limitations do not necessarily lead to disabilities. Help from others, special devices, or a barrier-free home compensate for the inconvenience caused by impairments. In addition, a person's expectations in performance, coping skills and psychosocial resources modify actual performance and functioning. All these aspects are considered to affect physical functioning. The WHO ICF framework includes enhanced participation, activity and personal resources as well as environmental factors. (WHO 2001.)

Physical functioning and disabilities can be measured by self-administered evaluations, using scales evaluated by professionals, or by performance-based measurements. All of them have strengths and limitations. Self-rated functioning gives a measure of functioning experienced in a person's own environment. Functioning in this sense depends on a person's motivation, cultural expectations, environmental requirements and possibilities besides the actual capabilities (Jyrkämä 2008). Cultural variations have been detected in a comparison of older men (70+) in three European countries in 1990: self-reported limitations in physical functioning were different in all countries, and association with performance-based functioning was positive. The Finns reported the fewest limitations but performed worse than the Dutch, whereas Italian males reported the worst functioning. (van den Brink et al. 2003.) Self-rated evaluation may overestimate performance in certain cultures or in challenging situations. In addition, these questions may not be well validated.

Figure 2:4. Overview of functioning. First the disablement process (Nagi 1975), modified after Verbrugge, Jette (1994) and Crimmins (2004). The International Classification of Functioning (ICF) is below (WHO 2001)



Professionals use scales (e.g. Barthel, Lawton, Katz) to assess various dimensions of older people's physical functioning (Katz et al. 1963, Mahoney & Barthel 1965, Lawton & Brody 1969). These scales describe daily functioning in the context in which it has been assessed (e.g. hospital) but may underestimate the performance in a person's home environment (Simonsick et al. 2001, van den Brink et al. 2003). These measures can easily be compared, and usually their validity and test-retest reliability are fairly well-known. Katz and Barthel scales are best validated for older people with poor functioning. Performance-based measures give objective and numerical information, for example, on a person's mobility performance (e.g. Short Physical Performance Battery, SPPB) (Reuben & Siu 1990, Freiberger et al. 2012). The SPPB is particularly rated good in terms of validity, reliability and responsiveness in community-dwelling older people, and it is a strong predictor of survival in the oldest-old (Cesari et al. 2008, Freiberger et al. 2012). It is recommended to use these performance-based measures in longitudinal studies (Cesari et al. 2008). However, these measures have only moderate correlation to actual daily functioning.

In a study setting and population-based assessments where objective measures cannot be applied, self-rated evaluations are used instead. This is the case, for example, in postal surveys, other questionnaires, or when data is collected by means of telephone calls. It has been shown that older people easily overestimate their performance in self-assessments. Additionally, the results may vary according to the precise inquiry: whether a person is capable of doing something, or whether he/she actually does it (Bootsma-van der Wiel et al. 2001). Compared with physical performance or muscle-strength measures, sensitivity to detect deterioration in physical abilities is very low in connection with self-assessments, whereas poor self-assessments are highly specific in identifying limitations in physical functioning (Brach et al. 2002, Cesari et al. 2008). When Christensen et al. interviewed and tested all 93-year-old Danes in 1998, the ADL scales showed moderate or good correlation with each other and with physical performance tests. Of these 93-year-olds, half of the men and two women out of five reported no disabilities in ADLs. One out of five reported severe disabilities. (Nybo et al. 2001.) There is a need for a simple and economical manner of ADL assessment.

2.3.4 Cohort trends among the old and the oldest-old

Research on successive cohorts of older people of the same ages helps to answer the fundamental question concerning increasing life expectancies of populations worldwide: does a longer life entail additional years of morbidity or disability, or could the period of morbidity and disability be compressed? The “compression of morbidity” paradigm was launched by Dr. Fries in 1980, proposing that by improving health behaviour one might not only extend life, but also postpone the onset of disability (Fries 1980). Some researchers state that medical progress will increase survival of the frail and as a result lead to an “expansion of morbidity” (Gruenberg 1977). Manton (1982) proposed a “dynamic equilibrium” between these two paradigms, which means that increasing survival rates will be offset by better control of chronic diseases (Manton 1982, Cambois et al. 2013). There are data supporting all these theories in various European countries (Rechel et al. 2013).

Ageing represents a process of gradual decline in functioning and eventual death with or without the presence of chronic diseases. At different stages of the ageing trajectory, health behaviours and the physical and social environment may influence intrinsic capacity and hence functional ability. There may also be significant changes in perceived health, wellbeing and disabilities among older people of the same age at different time points. Knowledge about cohort trends among the oldest-old is still scarce. (WHO 2001.)

The results of cohort trend studies are dependent on the participation rates of each cohort. Often the most dependent and frail do not respond. Thus, the representativeness and comparability of cohorts is an essential issue. There is a trend that later-born cohorts do not respond to these studies as comprehensively as earlier-

born cohorts. These problems in interpreting the findings have to be appraised critically in all cohort studies (Parker & Thorslund 2007).

Self-rated health

Cohort trends in SRH among the oldest share of population have not been consistent, and among the oldest share of the oldest-old the data is mostly missing (Table 2:3) (Martin et al. 2007, Parker & Thorslund 2007, Jylhä et al. 2013). Since the 1980s when SRH became a topic of interest in research, there seemed to be some increase in the percentage of older people (65+) reporting good health (Doblhammer & Kytir 2001, Crimmins 2004). At the same time the proportion of poor SRH was declining (Crimmins 2004). The improving time trend could not be verified in the 1990s and towards 2000. Instead, the results suggested either stable or worsening SRH before 2010, especially in the oldest age groups in the UK and Sweden (Spiers et al. 1996, Parker & Thorslund 2007, Galenkamp et al. 2012, Jylhä et al. 2013). In the *Vitality 90+* study in Finland, Jylhä explored trends in SRH and chronic conditions among all 90-year-olds and older in Tampere in 2001, 2003, 2007 and 2010. A trend of declining SRH was detected. (Jylhä et al. 2013.) Table 2:3 describes cohort studies of SRH.

Table 2:3. Studies of cohort trends in self-rated health (SRH) among older people

Study, country (study years)	**Participants, setting, design**	**Trend in SRH**	**Comments**
Spiers et al. 1996 UK (1981, 1988)	1981: n=1203 1988: n=1579, 75+ population-based, interview and performance tests	↓	in all age groups 75+
Dening et al. 1998 UK (1985-1992)	1985; n=2609 1988; n=1173 1992; n=628 75+ community-dwelling, interview and MMSE	↑	
Doblhammer & Kytir 2001 Austria (NA)	n=1773 (♀n=1262, 71%), 85-89 y population-based, interviews	60-84 y ↑ 85-89 y ↔	
Martin et al. 2007 USA (NA)	n>178 000 (appr. 8000 every year) 70+ community-dwelling, interviews	↑	Improvement more significant in young people but prevalent also in 70+ and 85+. Percentage of excellent SRH ↓
Karcharnubarn et al. 2013 Thailand (2002, 2007)	2002 n=24 835 2007 n=30 427 60+ y, population-based, community-dwelling, interview	↑	exception: ↔ ♂60-79 y
Jylhä et al. 2013 Finland (2001-2010)	n=4042, 90+ y, median age ♂ 91 y, ♀ 92 y in each survey, range 90-106 y. population-based, postal surveys, interview and performance tests.	↓	

MMSE = Mini-Mental State Examination. NA = not available

Comorbidities

Increasing prevalence rates of diseases have been reported in later-born older cohorts (Crimmins 2004, Parker & Thorslund 2007, Christensen et al. 2009, Crimmins & Beltrán-Sánchez 2011, Galenkamp et al. 2012, Hoeymans et al. 2012). This trend may reflect a more active approach in diagnosing older people´s diseases for which medications have become available (e.g. dementia, osteoporosis and benign prostatic hyperplasia). Increasing multimorbidity was reported in several countries in the 1980s and even 1990s among older people (aged 60–80 years), but the results are not unambiguous. However, in most studies the numbers of the oldest-old have been relatively small, the participants aged 75+ have been pooled together, or researchers have reported cohort trends before the year 2000. (Christensen et al. 2009.)

In the oldest-old population (85+ and especially 90+) the dynamics between disease incidence, prevalence and high mortality is complex. The number of diagnosed, documented and reported diseases may differ remarkably from the real morbidity of the older population (aged 80 years or more). Trends of comorbidities in nonagenarians are hard to explore (Crimmins & Beltrán-Sánchez 2011). In the Vitality 90+ study, the oldest-old were investigated, and as regards any single disease there were no changes in the number of chronic conditions in four successive cohorts between 2001 and 2010 (Jylhä et al. 2013). The mean number of relevant diseases among all centenarians in Denmark was 4.3 (SD 1.9) in 1995 (Andersen-Ranberg et al. 2001).

Psychological wellbeing

Time trends in PWB are not known. Published papers usually concern general adult populations instead of older people, not to mention the oldest-old. There are some items of PWB that have been studied more.

Loneliness among older people is of interest both in the media and in research. There is a trend of increasing loneliness in all age groups in long longitudinal analyses. In particular, the oldest-old report more loneliness than they did before. (Jylhä 2004, Cohen-Mansfield et al. 2009, Aartsen & Jylhä 2011, Dahlberg et al. 2015, De Jong Gierveld et al. 2016.)

In Jyväskylä the later-born 65–69-year-old cohorts of the Finnish Evergreen project in 2004 found life more *meaningful* than did their counterparts eight or 16 years earlier (Suutama 2006). Overseas, American later-born cohorts of men have been found to be less *content with their lives* than earlier birth-cohorts (Blanchflower & Oswald 2008, Steptoe et al. 2015).

Physical functioning

The results of numerous studies in the 20th century suggested that later-born cohorts of the oldest-old experience fewer functional limitations (Freedman et al. 2002, Moe & Hagen 2011) and fewer disabilities than earlier-born cohorts (Freedman et al. 2002, Manton 2008, Moe & Hagen 2011, Christensen et al. 2013).

Table 2:4 presents the findings of cohort studies. The prevalence of disabilities seemed to decrease up to early 2000 (Freedman et al. 2002, Crimmins 2004, Parker & Thorslund 2007, Manton 2008, Christensen et al. 2009). The future seemed bright and consistent with Fries´ hypothesis of compression of morbidity. However, some studies have suggested either a change for the worse, or a levelling-off of the improving functioning among older people since the beginning of the 2000s (Crimmins & Beltrán-Sánchez 2011, Sarkeala et al. 2011, Chen & Sloan 2015). Stable or worsening physical functioning has been especially reported in the younger-aged cohorts (Christensen et al. 2009, Seeman et al. 2010, Cambois et al. 2013).

Trends in the oldest-old are mixed (Parker & Thorslund 2007, Seeman et al. 2010, Sarkeala et al. 2011, Christensen et al. 2013, Chatterji et al. 2015). Data on the oldest-old suggest that cohort trends in physical functioning are not very prominent. Instead, age seems to remain the most important determinant of functioning among the very old (Jylhä et al. 2013). The need for care services (and for longer periods) has increased over last two decades among older people who are living their last two years of life (Aaltonen et al. 2017).

Table 2:4. Examples of studies of cohort trends in PHYSICAL FUNCTIONING among older people

Study Country (study years)	Participants	Setting/ methods	Major findings	functioning ↑/ ↔/ ↓
Crimmins et al. 1997, Schoeni et al. 2001 USA (1982-93-96)	n=5151-9000 70+ y	Cross-sectional, questionnaires or interview	improvement in all age groups	↑
Pitkälä et al. 2001 Finland (1989-99)	1989: n=685 (♀70-77%) 1999: n=2047 (♀ 65-78%) 75/80/85 y	Population-based, community-dwelling cross-sectional postal survey, questionnaire	physical functioning ↑ 85 y: go out ↑, need assistance ↓ 80 and 85 y: received home-care ↓	↑
Graham et al. 2004 New Zealand (1981,1996)	1981: n=6891 (♀60%) 1996: n=8262 (♀53%) 15+ y, 65+ y	Population-based, cross-sectional survey	minor increases in several disabilities, although institutionalization rates decreased	↓
Parker et al. 2008 Sweden (1980-2005)	appr. n=3000 in each survey, 65-84 y	Population-based, including institutionalized Interview with participant or proxy	ADL ↑ 1980-1996, ADL ↓ 1998-2005. Mobility ↑, hearing ↓. 80-84-y-olds: vision ↑	↑until 1995 ↔after 1995
Sulander et al. 2006 Finland (1993-2003)	n=11486 (3680-3993/study year) (♀ 50%), 65-84 y (25% 80+)	Population-based, mainly community-dwellers Questionnaire, every 2 years	use of stairs, walking outside ↑, BADL ↑ age and education are strong determinants	↑
Engberg et al. 2008 Denmark (1995, 2005)	1995: n=207 (♀ 78%) 2005: n=225 (♀ 84%) 100 y	Population-based, all Danes born in 1895/1905 Interview and assessments at home	BADL ↓ among women	↓
Seeman et al. 2010 USA (1988-2004)	1988: n=4688 (1988-94) 1999: n= 4239 (1999-2004). 60+ y	Cross-sectional Questionnaire, interview, clinical exam	60-69-y: more disabilities (except in function) ≥80 y: fewer functional limitations	↓↑
Moe & Hagen 2011 Norway (1987-2008)	total n=4036 (804-1311/ cohort) (♀ 58%) 67+ y, median age 75-76 y (80-84 y: 14-18%, 85+ y 7-15%)	Population-based, community-dwellers, cross-sectional. Interview (face-to-face at first, later mainly on phone).	Functional limitations (mobility) and disabilities (IADL, AADL) showed similar trends. High education protected from limitations	↑until 2005 ↓after 2005
Palacios-Cena et al. 2012 Spain (2001-6)	total 18 325 (♀ 62%) 65+ y (74Y)	Population-based cross-sectional, self-perceptions of community-dwellers	worsening (OR1.13), especially >84 years and obese	↓
Cambois et al. 2012 France (2003-8)	2871-13 682 (many data sets) mainly 50+, 65 y	Community-dwelling, face-to-face or questionnaire	limitations ↑ among 50+ y women gender gap narrowing in favour of males	↓
Freedman et al.2013 USA (2000-8)	1556-16 080 65+ y	Population-based, mainly community-dwelling 5 national data sets.	No significant overall trends. Activity limitations ↑ in middle age and ↓ in the oldest-old	↔
Jylhä et al. 2013 Finland (2001-10)	n=4042, 90+ y, 90-106 y median age ♂ 91y, ♀ 92y	Population-based, all citizens 90+, cross-sectional. Mailed survey, interviews	ADL independence↑, mobility ↔, mobility + ADL ↔ ♀: mobility ↓. Age: the most important determinant	↑↔↓
Karcharnubarn et al. 2013 Thailand (2002, 2007)	2002: n=24 835, 2007: n=30 427 60+, also group of 80+ y	Population-based, community-dwelling (households with a 60+ citizen), interview	BADL/self-care abilities ↓ Mobility ↑	↑↓
Christensen at al. 2013 Denmark (1998, 2010)	2262 (74%), 1584 (75%) 93 or 95 y	Population-based, all Danes born in 1903 or 1915 interview and assessment at home	Cognition ↑, ADL ↑	↑
Chen & Sloan 2015 USA (1996-2010)	each age group 1256-4511 53-88 y (grouped by 5y intervals)	Cross-sectional, biannual survey, mainly community-dwellers. Questionnaire and interview	large muscles and mobility ↓. the oldest: disabilities ↔, younger: additional impairments and disabilities	↓

2.4 OLDER PEOPLE´S PREFERENCES AND REALITY IN END-OF-LIFE CARE

2.4.1 Advance care planning among older people

Definitions

Advance care planning (ACP) allows people to state their own preferences for care, so that if they cannot make decisions themselves in the future, their wishes are known (Singer et al. 1996). The demand for planning is especially obvious in dementia and neurological diseases with prolonged inability to communicate coherently. Approximately one in ten decedents die suddenly and estimates of required and relevant decision-making processes vary between 40% and 70% of deaths in old age (Silveira et al. 2010, Scholten et al. 2018). *Living wills* (LWs) or *advance directives* (ADs) are usually documents that report some of the main guidelines of a person´s ACP for future treatments, or most often refusal to receive medical intervention or treatment (Laakkonen 2005). Citizens may also nominate a proxy with a *power of attorney* to participate in decision-making on their behalf in case they lose their mental or expressive capacity for choosing or forgoing the offered options for treatment (Laakkonen 2005). Most older decedents in the USA (70%) lacked decision-making capacity in the beginning of the 21st century, and two in three of them had completed a LW in a representative sample (Silveira et al. 2010).

Legislation and practical issues in ACP differ in various countries. In Finland, the Act on the Status and Rights of Patients (1992) states that a competent patient has to comply to either accept or forgo a proposed treatment (Finlex 1992). A person is encouraged to talk about preferences and wishes. Professionals must follow wishes to forgo active or aggressive treatments, including cases where a person is no longer competent to share their own views. A wish can be written as a living will, or it can be discussed with the physician earlier, and then be written in the chart. By far the most LWs in Finland include the idea of forgoing futile or aggressive treatments in cases where there is little hope of recovery. An AD is not binding as regards following a person´s wishes for special treatments. The practice has been rapidly changing since 2017, because patient preferences can be written in the health chart by a person him/herself through secure internet connections. This kind of AD can be seen in all health-care-provider settings in Finland. If there should be a discrepancy between a nominated trustee through a power of attorney and the AD, the AD or LW overrules. The majority of physicians are unaware of a patient´s existent AD in many other countries. Moreover, in countries such as Belgium and the Netherlands most people know about euthanasia but not about ADs, which may make them suspicious as regards ADs (Scholten et al. 2018).

Initiating ACP discussion

There is a shift of death and dying to older ages: among decedents in Finland, the median age was 85 years among females and 77 years among males in 2016, this being 2–3 years more than ten years earlier. Two in

three of all decedents were at least 75 years old, and one in three more than 85 years old (Official Statistics of Finland 2017). Most older people are willing to talk about life, death and dying, but they seldom have the opportunity to do this with health-care professionals. Additionally, they often prefer to talk to their significant ones (Laakkonen et al. 2004, Bernacki et al. 2014, Fleming et al. 2016, Scholten et al. 2018). A minority of severely ill older people talk about death with their GPs (Covinsky et al. 2000, De Vleminck et al. 2013, Scholten et al. 2018). Conversations about EOL treatments and death are more frequent among women and older people, especially among those with poor health, and among patients who have paid a lot of visits to GP practices (De Vleminck et al. 2015). Furthermore, a frequent demand for understandable face-to-face communication with the families of dying individuals cannot be put on the shelf: only around half of the family members of residential care-home decedents understood what the doctor told them (60%), knew the situation (50%), or were kept informed (60%) in a large retrospective survey in the USA. The study confirmed that the most content were those proxies who talked with the physician face-to-face or understood the approaching death. (Biola et al. 2007.)

Barriers to discussion of end-of-life issues appear to be more common among physicians than patients (Keating et al. 2010, Bernacki et al. 2014). Many primary-care physicians feel themselves incompetent to launch discussions about ACP, or they may not feel comfortable about the right timing. Often, they don´t find enough time for conversations. They also expect that the patient should initiate the discussion. Sometimes they are fearful of removing hope, or emerging needs that cannot be met. (De Vleminck et al. 2013, Howard et al. 2015.) In contrast, among facilitating factors for commencing ACP are accumulated skills, skills in responding to a patient´s initiative, ability to foresee health problems, long-standing patient–GP relationships and the home setting (De Vleminck et al. 2013). The timing of EOL discussions is difficult to optimize. Therefore, a common way to proceed is to write down preferences at the time of becoming institutionalized. When new nursing-home residents with advanced dementia or terminal cancer were evaluated at admission in New York, only 1% of the residents had an estimated life expectancy shorter than six months. However, 71% died within that period. Even now, there are no valid ways to predict length of life (Mitchell et al. 2004).

Advantages of advance care planning

There is ample and recent data about the advantages of ACP. Discussions involved in ACP stimulate communication between patients, proxies, and physicians, thus resulting in better satisfaction in EOL care, although opposite results also exist. Support in decision-making is obvious. ACP alleviates suffering and improves quality of life. Family members report less anxiety, depression and stress. Furthermore, ACP is essential in access to palliative care. It also has a beneficial influence on societies in reducing the cost of EOL care. In the early 1990s before extensive projects to develop EOL care in the USA, hospital deaths as well as transfers from nursing homes to hospitals were less common among those who had a living will (Molloy et

al. 2000, Degenholtz et al. 2004, Detering 2010, McMahan et al. 2013, Auriemma et al. 2014, Scholten et al. 2018).

Patient preferences are not stable over a lifetime. Signing an AD or LW document does not necessarily result in care more congruent with patient preferences (Covinsky et al. 2000, Collins et al. 2006, Cohen-Mansfield & Lipson 2008, Biola et al. 2010). In some studies various population samples have responded to questions about treatments in certain health scenarios, in order to use the results in public-health planning. These scenarios are widely used in AD documents in different countries. However, not many people are capable of imagining the scenarios and taking a stand in advance (Tsevat et al. 1999, Auriemma et al. 2014). Patient wishes often change, especially among older people without serious diseases (Sigurdardottir et al. 2012, Auriemma et al. 2014). Older people engaged in ACP, or with a high educational level have greater preference stability, along with those who prefer to forgo treatments instead of choosing aggressive treatments. In a review paper 59 articles about stability of preferences were explored and the results suggested that care preferences change in 30% of people (Auriemma et al. 2014).

Older experienced people and medical decision-makers found mutual understanding in several focus groups concerning ACP in the USA recently. Instead of simply constituting a living will, ACP fulfils its mission, if 1) values based on experiences and QOL are identified first, and if 2) surrogates are chosen wisely. It has to be verified that the surrogates understand their role properly. Additionally, they found it important to 3) decide what kind of flexibility will be acceptable for surrogate decision-making. Last, 4) family and friends have to be informed of the wishes to prevent later conflicts. (McMahan et al. 2013.)

Prevalence of advance directives

Despite efforts to make the topic of death and dying discussed more widely, the prevalence of written ADs is low in most European countries. Even if with a terminal illness, less than half of the patients have a written AD (Scholten et al. 2018). In Belgium and the Netherlands only 3.6% of very seriously ill patients had prepared a negative AD to forgo certain interventions (Scholten et al. 2018). The percentage of citizens with any kind of written AD is low in the general population in the UK as well (8%) (De Vleminck et al. 2013). On the other hand, in these countries continuity in primary care is strong: GPs may visit patients even in a hospice or hospital, which may increase concordance in decision-making (Michiels et al. 2007). Few people have completed an AD although they intend to do so. Eighteen per cent of cancer patients, 19% of healthy controls, and only 10% of medical professionals had an AD in Germany 15 years ago. Half of the participants were worried about being forced to write an AD and feared misuse of ADs by their families. Not many of them knew of the possibility to name a health care proxy. (Sahm et al. 2005.) The prevalence of LWs or other ACP documents in Finland is not known; at the beginning of the 2000s some surveys suggested that 15% of older people (75+), 13% of physicians, 20% of nurses and only 5% of hospitalized patients had completed a living

will (Hilden et al. 2004a, Hilden et al. 2004b, Laakkonen et al. 2004). Since then, public discussion about power of attorney has increased.

The USA is way ahead of Europe in promoting ACP. *The Patient Self-Determination Act* (PSDA) in 1990 was supposed to improve a patient´s right to make direct health-care decisions. Advance directives were the means to control medical care (United States General Accounting Office 1995). *SUPPORT* (the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) was a large study carried out to explore the state of dying in the USA and to evaluate interventions after the launch of the PSDA. The results were not promising, though. The number of ADs in the medical records increased from 6% to 35% during the SUPPORT intervention and further to 72% in 2010 (De Vleminck et al. 2013, Silveira et al. 2014), but this increased documentation was not associated with changes in care or use of hospital resources. It took 15 years since the PSDA and 10 years since SUPPORT to increase the number of ADs, but the ADs seldom followed the patients in health charts. Three of four physicians were unaware of their patient´s AD. Care was inconsistent, with written instructions in the AD in half of the cases (Collins et al. 2006). There are exceptions with remarkable changes in EOL care locally: in a community of almost 100 000 inhabitants in Wisconsin the prevalence of LWs increased up to 85% in the mid 90s, due to large campaigns with educational material and help provided to both lay people and professionals. Nearly all LWs were well documented in health files (95%), and EOL care was very much consistent with patient preferences. (Hammes & Rooney 1998.)

2.4.2 Intensity of care

Many people have an idea about the intensity of care that they are willing to experience. However, data on the convergence between wishes and reality at the end of life is insufficient. Many studies have been carried out by interviewing proxies or physicians after death, thus presenting a bias: do the proxies or physicians remember? Did they even know the patient preferences? (Covinsky et al. 2000, Biola et al. 2007, Silveira et al. 2010, Pasman et al. 2013, Fleming et al. 2016.)

The intensity of treatments or care has not been accurately defined. Hospitalizing near death, referring to an intensive care unit, ordering burdensome diagnostic tests or performing painful procedures such as resuscitation or i.v. infusions at the close of life can be defined as intensive or high-intensity treatment, or even aggressive care. Likewise, life-prolonging treatments or aims to cure the incurable are among non-beneficial medical procedures. (Laakkonen 2005.)

A large-scale systematic review of non-beneficial treatments in hospitals at the EOL revealed both the difficulties to predict imminent death and the high number of non-beneficial medical procedures that older people experience during their last months. One in three terminal-stage older people experienced futile treatments: resuscitation attempts, transfusions, dialysis, radiotherapy, or non-beneficial antibiotics.

However, the range of percentages in different studies was large, suggesting variety in care culture in different parts of countries and the world. (Cardona-Morrell et al. 2016.)

Living wills and intensity of care

When the oldest-old discuss EOL care, they often express their resilience: they are ready to go. Most of them wish to forgo all life-extending procedures at the close of life. Concurrently they may be strongly attached to life. A palliative approach to care options does not always capture the same thoughts among both physicians and the oldest-old. Most of the oldest-old with a completed LW wish to be resuscitated in their current state of health. Furthermore, family members are seldom well aware of patient preferences. (Covinsky et al. 2000, Laakkonen et al. 2004, Collins et al. 2006, Fleming et al. 2016.) Therefore, researchers can only make an assumption that the presence of a LW document should prevent a dying person from burdensome treatments. Opinions of lay people and medical professionals are similar, with an optimistic view that LWs improve decision-making to better accommodate patient preferences (Hilden et al. 2004a, Hilden et al. 2004b, Higel et al. 2019). Current research on the reality is scarce and contradictory.

In many countries older people express their willingness to withhold certain active treatments in EOL care. According to reviews, a living will is associated with less intensive treatments in those who wish so (Hammes & Rooney 1998, Silveira et al. 2010, Tschirhart et al. 2014). Some older studies reported that the concordance between preferred and received care was better in those who wanted to forgo life-prolonging care than those who preferred active treatments (Jacobson 1996, Cosgriff et al. 2007, Parr et al. 2010, Silveira et al. 2010). In the Longitudinal Aging Study Amsterdam, concordance between ADs and actual treatment was high in those older people who wished to choose active treatments, but significantly lower in those older people who had chosen to forgo life-sustaining treatments. However, they could still prove that making an AD to forgo futile treatments increases the possibility of receiving only preferred treatments. (Pasman et al. 2013.)

Though uncertainty concerning the effect of a living will on intensity of care remains, an LW document seems to ease decision-making and improve quality of life (Jacobson 1996, Auriemma et al. 2014, Scholten et al. 2018).

Other associations with intensity of care

Other patient-related factors may affect treatment decisions in daily practice as well. The oldest-old receive less burdensome treatments than younger old (Tschirhart et al. 2014). Gender plays a role in at least patient preferences: females are less likely to be willing to prolong their lives by medical interventions in hypothetical health scenarios (Covinsky et al. 2000, Carmel 2001). In the USA black people experience more intensive

treatments during the last six months of life. However, being a resident in a nursing home is associated with a lower likelihood of intensive treatments (Tschirhart et al. 2014).

Cancer patients most often avoid intensive procedures. Patients with advanced dementia experience more burdensome interventions than cancer patients, but in some studies treatments are more aggressive among non-demented patients. (Mitchell et al. 2004, Tschirhart et al. 2014.)

There are associations other than patient-related ones in decision-making towards EOL. Experienced physicians decide to forgo some active or even aggressive treatments more often than their young colleagues, who often tend to do their utmost (Spence 2012). This was seen in a retrospective study where decisions to resuscitate or not were analysed in all cardiac-arrest cases in hospitals (Einav et al. 2012). Geographical factors seem to have an effect on intensity of care as well. The likelihood of undergoing an intensive procedure is doubled in a region with higher numbers of hospital beds (Tschirhart et al. 2014). An issue of feeding-tube insertion when death is nearing is an example of cultural factors. It is a real matter for research and clinical practice in the USA (Teno 2011), but not among the challenges for decision-making in Scandinavia.

2.4.3 Site of death

Most people choose to die at home, but end up dying elsewhere (Abarshi et al. 2009, Meeussen et al. 2009, Murtagh et al. 2012). It is estimated that one third of older people will die at the place they prefer (Bell et al. 2010). In studies of cancer patients in particular, the percentage wishing to die at home is most often over 50%, whereas among older people with chronic conditions the percentage is somewhat lower (42–48%) (Murtagh et al. 2012). In the Western world the choice concerning the place of death is embedded in a good death (Pocock et al. 2016). However, the preferred site of death may change with increasing symptoms or frightening experiences (Fleming et al. 2010, Murtagh et al. 2012). Thus, even a hospital death may be well aligned with changing patient preferences (Pocock et al. 2016). Although many older people wish to die at home, few of them have reported their wishes (Scholten et al. 2018). However, shared decision-making about end-of-life care is more common among those who die at home (Cohen et al. 2007). On the other hand, some studies suggest that discussions with the family or caregivers take place more rarely at home (Cohen et al. 2007).

Increasing disabilities with age lead to end-of-life care transitions when death is nearing (Aaltonen et al. 2017). Most older people live at their homes until the last months of their lives in Western countries (Van den Block et al. 2007, Larsson et al. 2008, Aaltonen et al. 2010, Fleming et al. 2010, Aaltonen et al. 2017), but less than 10% of older people experience no care transitions at all from home during the last six months of life (Larsson et al. 2008, Fleming et al. 2010, Aaltonen et al. 2017). In particular, older community-dwelling people with dementia experience more care transitions during the last years of life, compared with other

community-dwelling older people or institutionalized dementia patients (Aaltonen et al. 2012). Concurrently with attempts to increase the proportion of those dying at home, data from the USA showed increasing transitions to hospice care during the last three days of life from 2000 to 2009. Indeed, deaths in acute hospitals decreased from 32% to 25% and use of hospice care increased from 22% to 42%, but use of intensive care units in the last month of life increased from 24% to 29%. Increases were also seen in care transitions in both the last 90 days and the last three days of life. (Teno et al. 2013.) Additionally, during the same 10-year period, more older people were hospitalized at least once in the last two years of life (from 52% to 72%) (Silveira et al. 2014).

In large register-based studies throughout Europe and the USA the results resemble each other: half of older decedents die in hospitals. Among the oldest-old in the UK, two in five die in acute hospitals, and one in 10 in a long-stay hospital ward. Two thirds of the oldest-old live at their homes one year before death, and as many as one third of them also die at home. The oldest decedents (>90 years old) experience fewer transfers during their last year than do younger 85–89-year-olds. (Fleming et al. 2010.) As many as one in five older decedents die at home, whereas roughly one in four dies in a nursing home. Belgium is an example of a country where general practitioners care for dying persons both at home and in care homes and palliative units. There, the share of hospital deaths is lower (40%), home deaths are common (24%), and number of hospice deaths is remarkable (10%). (Mitchell et al. 2005, Van den Block et al. 2007, Aaltonen et al. 2010, Pocock et al. 2016.) Home deaths are rare in Finland, since only 15% die at home (Aaltonen 2015).

It seems to be beneficial to have EOL discussions. Carrying out such discussions reduces care transitions from nursing homes to hospitals during the last months of life according to a French study (Morin et al. 2016). Assigning a durable power of attorney may also reduce hospital deaths (Silveira et al. 2010). Fortunately, there is also data on the association between having a living will and a lower probability of dying in hospital among both community-dwelling older people and nursing-home residents (Degenholtz et al. 2004).

There are several other *factors associated with site of death.* Age, gender, residency and diagnosis seem to be better predictors than other factors. Males, younger olds (70+), people with a non-malignant diagnosis (heart failure, lung disease or hip fracture) die more often in secondary/tertiary hospitals, whereas females and the very old ones, especially those with dementia, die more often in residential-care homes or health centres. Cancer patients die more often at home compared with decedents with different diagnoses. Residents in assisted living or other institutions are rarely transferred to hospitals before death. (Mitchell et al. 2005, Aaltonen et al. 2010, Biola et al. 2010, Pocock et al. 2016.) At the state level, even the availability of hospital and nursing-home beds seems to affect the variation between deaths in hospitals, homes or nursing homes (Mitchell et al. 2005).

2.5 SUMMARY OF THE LITERATURE

Self-perceptions and wishes concerning remaining years are different among younger adults and older people. WTL is familiar to everyone, but until this study, research on it had just begun. Simple inquiries have been widely used to assess SRH, but otherwise assessments of health, wellbeing and functioning have been done mainly by way of objective measurements and these domains have not been combined in studies.

The oldest-old and centenarians see their ageing as an evident thing in life. Negative and positive attitudes towards ageing affect their lives and behaviours and even moderate their own preferences (Warmoth et al. 2016).

Health and physical functioning have improved among older people for decades. Similar trends have been observed in SRH, along with increasing morbidity. Toward and after the year 2000 the trends have not been clear: in some respects, there is still improvement; in some domains functioning is getting worse. The middle-aged in particular have shown trends of levelling-off or even worsening in the USA and France.

Efforts to increase the numbers of documented LWs and other ADs have not necessarily led to care more congruent with patient preferences. The existence of an AD is not enough. Knowing the values of older people and what they wish to achieve can be of benefit in setting and reaching their goals (Hicks & Siedlecki 2017).

3 AIMS OF THE STUDY

The main aim of this study was to explore older people's self-perceptions concerning their health, wellbeing and functioning, and their wishes concerning the length of their lives and end-of-life care.

Specific aims were as follows:

1. To explore older people's own wishes concerning their length of life (I, II).
2. To evaluate whether older people's own wishes concerning their length of life predict survival (I).
3. To explore older people's reasons to live or not to live to an extremely old age (II).
4. To investigate time trends in health, psychological wellbeing and disabilities among the oldest-old over two decades (III).
5. To examine the associations between having a living will and the intensity of end-of-life care, and the site of death (IV).

4 MATERIAL AND METHODS

4.1 PARTICIPANTS

Overview of study participants

The participants of this population-based research were community-dwelling older people in Helsinki, aged 75–96. They were subjects of the Helsinki Aging Study (HEVA= Helsingin vanhustutkimus) and/or DEBATE (Drugs and Evidence-BAsed medicine in The Elderly), for which random samples of older people were retrieved from central registers of the population information system in 1989, 1999 and 2009 (Strandberg et al. 2001, Strandberg et al. 2003, Tilvis et al. 2004) (Table 4:1). All participants received a postal questionnaire, followed by one additional reminder to respond after one month of non-response. Those who were already institutionalized were excluded from the analyses. The flow chart of the studies for this thesis is shown in Figure 4:1, below. Table 5:1 in the Results section illustrates more demographic data at baseline.

Table 4:1. The participants of the Helsinki Aging Study (HEVA) and DEBATE in specific studies for this thesis

Study	Participants	n	mean age, y (range)	females, %
I **Will-to-live**	Cardiovascular participants of the DEBATE study, baseline in 2000 (≥ 75 years), ten-year follow-up until 2010	283	79.1 (75-90)	62.2
II **100?**	Population-based random sample in 2009, ≥ 75 years (HEVA)	1405	83.7 (75-96)	69.4
III **Cohort trends**	Cohorts from population-based random samples in 1989, 1999 and 2009 (samples of 75/80/85/90/95-year-old community-dwelling people), four-year follow-up for mortality for each cohort (HEVA)	4895	82.0 (75-95)	70.7
IV **Living will and end-of-life care**	Deceased cardiovascular participants of the DEBATE study, baseline 2000 (≥ 75 years), ten-year follow-up until 2010	207	82.1 (75-91)	63.8

Cardiovascular participants of DEBATE in Studies I and IV

The participants in Studies I (n = 283) and IV (n = 207) were subjects of the randomized controlled cardiovascular prevention trial DEBATE (n = 400) (Strandberg et al. 2001, Strandberg et al. 2003). Briefly, the DEBATE study was designed to test the effectiveness of multi-component intervention among 400 aged cardiovascular patients. These participants were thoroughly examined at baseline by a study nurse and doctor in 2000 and 2001, and they were followed for years. Each participant had been diagnosed with a major cardiovascular disease. (Strandberg et al. 2006.)

Study I: The participants of the first study comprised those people in the DEBATE study who responded to the inquiry "*How many years would you still wish to live*?" at baseline in 2000. The response rate was 70.8% (n = 283) of all 400 eligible participants of DEBATE, and their mean age was 79.1 years at baseline.

Study IV: The death certificates of all deceased participants of DEBATE were retrieved for Study IV. Of those 378 participants in DEBATE who had responded to end-of-life questions in 2000 (response rate 94.5%), 207 participants had died during the 10-year follow-up period to January 2010. Their mean age was 82.1 years at baseline. All 207 death certificates were analysed for Study IV.

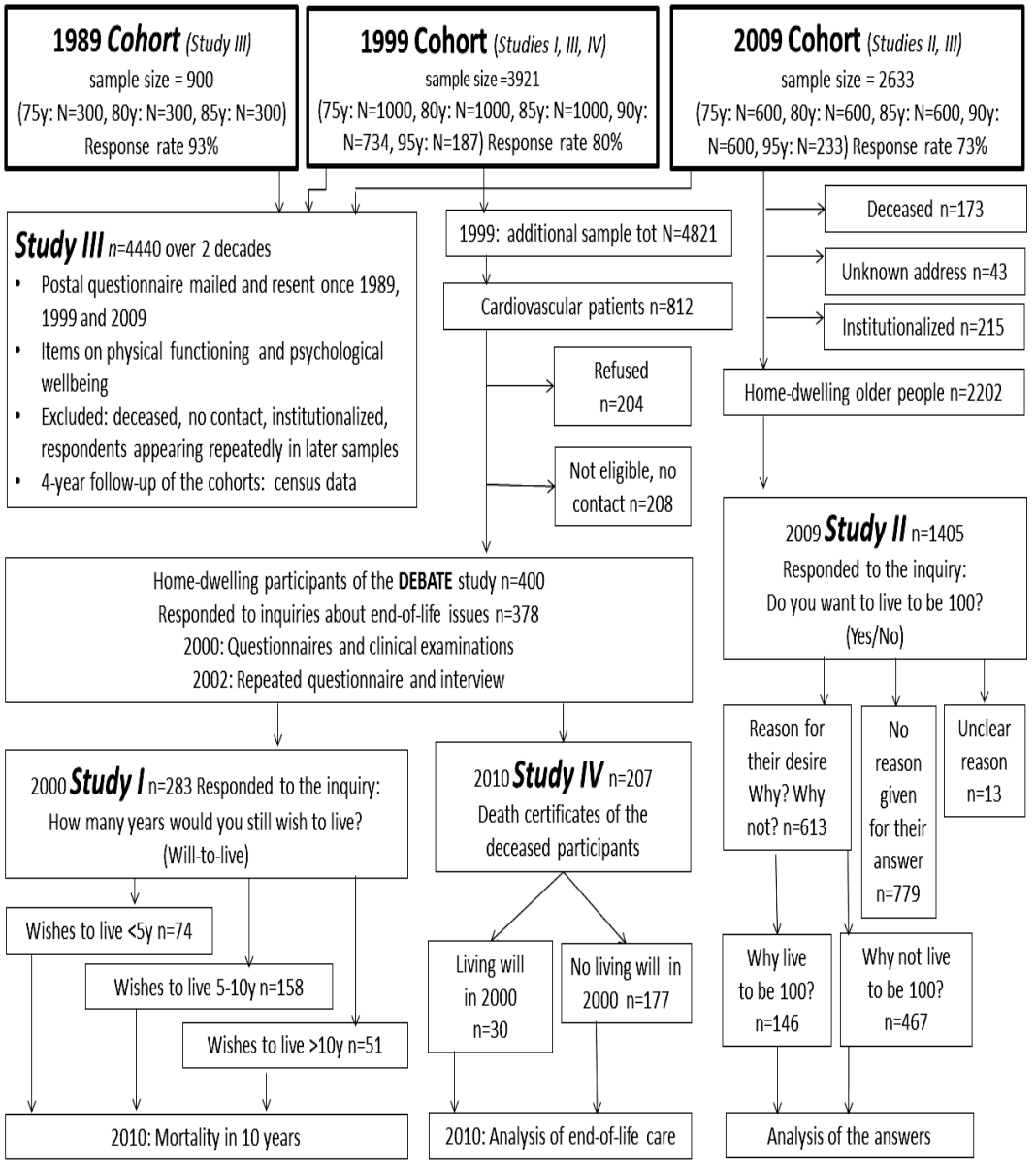
Community-dwelling older people for Study II

Study II: The latest structured self-completed questionnaires in 2009 were used as a source of data for Study II. A random sample of older people (N = 2633) at ages 75, 80, 85, 90 (N = 600 in each age cohort) and 95 (all, N = 233) living in Helsinki, was drawn from the Population Register Centre. The questionnaire was sent in October 2009 and re-sent once to those who had not responded. Those who had died, who were permanently institutionalized or of unknown address were excluded (N = 431). The overall response rate to the questionnaire was 74.3% (n = 1637 of the eligible 2202 community-dwelling people). The respondents were younger (83.7 vs. 84.7, $p < 0.001$) and more often males (31.2% vs. 26.3%, $p = 0.007$) than those who did not return the questionnaire. Of the eligible 2202 people, 63.8%, and of the respondents, 85.8%, answered the specific question "*Do you want to live to be 100?"* (n = 1405). These 1405 participants of Study II did not differ from those respondents who did not answer the inquiry about surviving to 100 years (n = 232), in respect to age or gender.

Samples over two decades for Study III

Study III: Cohort data for Study III were retrieved from postal questionnaires, and mortality data on all random samples of the HEVA study at three time-points over two decades: 1989, 1999 and 2009 (n = 4895). Random samples of community-dwelling people in Helsinki were drawn from the population register in 1989 (N = 898; 300 each in the 75- and 80-year-old groups and 298 in the 85-year-old group), in 1999 [N = 3921; 1000 each in the 75-, 80- and 85-year-old groups in addition to all 90-year-olds (N = 734] and all 95-year-olds (N = 187]), and 2009 [N= 2633; 600 in each of the four age groups from 75 to 90, and all 95-year-olds (N = 233]). The questionnaire, with identical items, was mailed to eligible people and re-sent once to those not responding at each time point. Persons with unknown addresses, the deceased and those who were permanently institutionalized were excluded. The response rates in 1989, 1999 and 2009 were 93% (n = 660), 80% (n = 2598) and 73% (n = 1637), respectively. The mean age of all participants was 82.0 years.

Figure 4:1 Flow chart of all four studies in the thesis



4.2 METHODS

This epidemiological, empirical and descriptive research involved both cross-sectional (Studies II, III) and longitudinal (Studies I, III, IV) approaches. Two studies described the 10-year follow-up investigations, where survival over a ten-year period was examined with respect to will-to-live, and a living will document at baseline (Studies I and IV). In addition, Study III involved a 4-year follow-up period in regard to mortality, the study being otherwise a cohort study over two decades. (See Table 4:2.)

Table 4:2. Overview of study methods in specific studies for this thesis

Study			
I **Will-to-live**	longitudinal, 10-year follow-up	questionnaires, interviews and clinical exam, census data	quantitative
II **100?**	cross-sectional, descriptive	postal survey	qualitative (thematic content analysis) and quantitative
III **Cohort trends**	population-based, cross-sectional, cohorts over 20 y	postal survey with census data	quantitative
IV **Living wills and end-of-life care**	longitudinal, retrospective, descriptive	questionnaires, interviews and clinical exam, census data; analysis of the death certificates	qualitative and quantitative

4.2.1 Measures

A structured self-completed postal questionnaire was mailed to possible participants of the study and resent once to remind the non-responders. The questionnaires were mailed during late autumn in 1989, in mid-winter in 1999, and the 2009 questionnaires were mailed in summer. The questionnaire included several demographic items, as well as medical and physical issues. Specific items concerned age, gender, marital status (married or cohabiting/unmarried/divorced/widowed), housing (home/assisted-living facility/dementia unit or nursing home/hospital), education (primary school/vocational school/high school or college degree/university degree), categorized as primary school (education < 8y) vs. others, smoking (never smoked/ever smoked).

Certain symptoms were inquired about via yes/no questions (e.g. depressive feelings over a fortnight). In the questionnaire the participants were also asked for a list of prescribed medications. This was a way to count

the number of drugs. In addition, there were several items about preferences, or perceptions of functioning, followed by a few open-ended questions. Additionally, in all studies there were extra questions or interviews depending on the research question. In Studies I and IV, MMSEs were administered by the study nurse to assess cognition at baseline (Folstein et al. 1975).

The main measures are described in Table 4:3.

Table 4:3. Measures or tools used for each study in this thesis

Measure or tool	study	essential
Postal questionnaire	I-IV	demographics, health and functioning, perceptions and preferences of getting old or dying
Charlson comorbidity index (Charlson 1987)	I-IV	A measure of comorbidities
SRH (self-rated health)	I-IV	Inquiry: How is your health? healthy/quite healthy/quite unhealthy/ unhealthy
MMSE (Mini-Mental State examination) (Folstein 1975)	I, IV	A tool to reflect the level of cognition; assessed by the study nurse
WTL (will-to-live)	I	Inquiry: How many years do you still wish to live?
Willingness to live up to 100	II	Inquiry: Do you wish to live up to 100 years? Why/Why not?
PWB (psychological wellbeing)	III	A score of six dimensions in self-rated psychological wellbeing: (1) life satisfaction (yes/no), (2) feeling useful (yes/no), (3) having plans for the future (yes/no), (4) having zest for life (yes/no), (5) feeling depressed (seldom or never/sometimes/often or always) and (6) suffering from loneliness (seldom or never/sometimes/often or always)
Self-reported physical functioning	III	Three separate inquiries: (1) Do you go out on a daily basis? (yes/no), (2) Do you need help from another person on a daily basis? (yes/no), and (3) Do you need help from another person to get out of bed? (yes/no)
SMR (standardized mortality ratio)	III	Mortality of the participants compared with census data of their background population

Comorbidities

Each diagnosed major disease was inquired about with a yes/no question in the questionnaires. The *Charlson comorbidity index* was calculated according to the occurrence of diagnosed major diseases (Charlson et al. 1987). It includes severe diseases that affect prognosis for an individual, and both the number and severity

of diseases are considered. In this study the Charlson comorbidity index was calculated using data on history of cancer, congestive heart failure, stroke, myocardial infarction, peripheral vascular disease, dementia, chronic lung disease, connective tissue disease, ulcer, chronic liver disease, diabetes, and moderate or severe kidney disease. In Studies II and III the diagnoses that were reported by the participant in the postal questionnaire were considered. The respondent was asked to report whether he/she had been diagnosed with these specific diseases by a physician. Additionally, in Studies I and IV the responses could be verified in the health charts as well.

Self-rated health

The respondents were asked to think about their health. They were asked "How is your state of health?", and were invited to respond with one of the choices: "I consider myself healthy/quite healthy/quite unhealthy/unhealthy". This *SRH* was then categorized as either "good" (healthy/quite healthy) or "poor" (quite unhealthy/unhealthy). At the beginning of the question there was no temporal adjunct like "during the last two weeks", or "compared with other people of your age" etc.; instead the question was put directly.

Will-to-live and preferences concerning end of life

The participants of the first study were asked how many years they would still wish to live (WTL), at baseline in 2000–2001. They were further asked whether they had made a living will (yes/no), for Study IV, to be analysed after the ten-year follow-up. Respectively, in 2009 the participants of Study II were asked about willingness to live up to 100 years (yes/no), and then invited to give a reason for their answers (Why? /Why not?).

Psychological wellbeing

The questionnaire evaluated *PWB* according to responses to six questions (Tilvis et al. 2000, Pitkälä et al. 2004). The questions inquire about (1) life satisfaction (yes/no), (2) feeling useful (yes/no), (3) having plans for the future (yes/no), (4) having zest for life (yes/no), (5) feeling depressed (seldom or never/sometimes/often or always) and (6) suffering from loneliness (seldom or never/sometimes/often or always) (Pitkälä et al. 2004). Responses of "no" to questions 1–4 and "often or always" to questions 5 or 6 contribute zero raw points to the aggregated score. Responses of "sometimes" to questions 5 or 6 contribute to the total with 0.5 raw points. Responses of "yes" to questions 1–4 and "seldom or never" to questions 5 or 6 contribute 1 raw point each to the total score. A total PWB score was created from the responses to these six questions. The PWB score for each study participant was then calculated by dividing the sum total of raw points by the number of questions the participant had answered. A score of 1 represented the best possible PWB score and 0 the poorest (Routasalo et al. 2009). These six questions show good test-retest reliability (Savikko et al. 2006) and significant prognostic validity as regards mortality (Pitkälä et al. 2004).

Self-reported physical functioning

All questionnaires over two decades (1989, 1999 and 2009) included identical inquiries: “Do you go out on a daily basis?” (yes/no), “Do you need help from another person on a daily basis?” (yes/no), and “Do you need help from another person to get out of bed?” (yes/no). These questions were found easy and relevant for older people to understand and respond to in 1989 (Valvanne 1992).

4.2.2 Analyses

Qualitative analyses

Thematic content analysis (Pope & Mays 1995, Silverman 2000) was applied in Study II, where responses to the open-ended question “Why live/Why not live to be 100?” were analysed. All responses to the open-ended question of living extremely long were systematically examined several times to identify the initial thematic framework. The data were then organized and classified using initial codes which were further grouped into broader categories encompassing the initial codes. Each item was compared with the rest of the data to establish analytic themes (constant comparison). All categories were grouped into analytic themes. Tabulations were used to determine frequencies in the categories.

In Study IV, death certificates were explored for relevant content analysis regarding the event history and place of death.

Statistics

The data are presented as percentages and means with standard deviations (SDs). The Chi-square test and Fisher´s exact test were used for comparing groups in regard to categorial data and Student’s *t*-test, the Mann–Whitney *U*-test or the Kruskal–Wallis test were used for continuous variables, as appropriate. A two-sided p-value of < 0.05 was considered to indicate statistical significance.

In Study I, Cox’s proportional hazard model was used to determine how WTL predicted survival, with the < 5-year WTL group as a reference, and the data adjusted for age, gender, educational level, comorbidity, smoking habits, feelings of depression and MMSE score. The underlying proportional hazards assumption was tested by computing the Schoenfeld residuals for each of the covariates in the final model and plotting them against the length of survival. Unadjusted Kaplan–Meier curves were constructed for total mortality from baseline to death or to the end of the follow-up period in all three WTL groups and the Log-rank test was used to compare Kaplan–Meier curves.

In Study II, a multivariate logistic model was used to explore associations with willingness to live up to 100 years.

In the cohort study (Study III) generalized estimating equation (GEE) models were used to determine the adjusted relationships between the samples of age groups over the study years to find time trends. The models consisted of the main effects (year and age) and their interaction. All analyses performed were adjusted for gender, education and widowhood. The normality of each variable was tested by using the Shapiro–Wilk *W* test.

The analyses were performed using either NCSS or STATA software (version 13.1), StataCorp, LP, College Station, TX.

Standardized mortality ratio

For Study III, data on 75, 80, 85, 90 and 95-year-olds were collected at three time-points over two decades and compared, i.e. the 85-year-old people in 2009 with the 85-year-old people in 1989 and 1999. To tackle the selection bias with decreasing response rates, the representativeness of each sample needed to be assessed. SMRs were calculated for each study sample so that the actual mortality in each study sample could be compared with the whole Finnish population of respective age. The mortality data were retrieved from central registers during a four-year follow-up period.

The precise number of days of survival during this four-year follow-up was counted for each participant in the samples. The expected number of deaths was calculated on the basis of sex-related, age-related and calendar-period-specific mortality rates of the Finnish population at that time. First the SMR was calculated as the ratio of observed and expected number of deaths according to Statistics Finland. The corresponding 95% confidence intervals (CIs) were defined assuming a Poisson distribution of the observed number of deaths. An SMR of 1 means that mortality is the same in the study group and the background population. An SMR below 1 reflects the fact that the study group survived longer than the background Finnish population of the same age and gender.

4.2.3 Ethical considerations

The research protocol of the DEBATE study was approved by the Ethics Committee of the Department of Medicine, University of Helsinki, and the Helsinki Aging Study protocol was approved by the Helsinki University Hospital Ethics Committee. The participants in Studies I and IV received both oral and written information about the study before their oral consent, followed by written informed consent. The items of WTL, death and ACP were inquired about by a study nurse with experience of caring for cancer patients and discussing matters related to end-of-life care.

5 RESULTS

5.1 CHARACTERISTICS OF PARTICIPANTS

The participants of this study were older people (aged 75+) living in Helsinki. The random samples were retrieved from Population Information System in 1989, 1999 and 2009. Institutionalized people were excluded at baseline. Thus, the participants represented home-dwelling older people. The mean age of the participants in the four studies varied between 79.1 and 83.7. The overall number of the oldest old (85+ years) respondents was 1737. The range of proportion of females was 62.2–70.7% and that of widowed people 39.5–46.9% (Table 5:1).

Table 5:1. Characteristics of participants in studies I-IV

	I (will-to-live)	II (100 years)	III (cohorts)	IV (end of life)
n	283	1405	4895	207
Mean age, years (SD)	79.1 (4.6)	83.7 (6.3)	82.0 (5.8)	82.1 (4.9)
Females, %	62.2	69.4	70.7	63.8
Widowed, %	39.5	42.1	43.9	46.9
Education < 8y, %	55.6	37.2	48.4	57.5
Charlson index, mean (SD)	2.3 (1.4)	2.1 (1.8)	2.0 (1.9)	2.4 (1.4)
Good self-rated health, %	73.1	73.9	70.3	58.5
MMSE, mean	26.6 (2.3)	NA	NA	25.8 (2.7)

SD = Standard Deviation, NA = not applicable

5.2 WISHES FOR A LONG LIFE (I AND II)

5.2.1 WTL as a predictor of survival (I)

How many years would you still wish to live? Of the 400 eligible participants with a cardiovascular disease in the DEBATE study, 70.8% responded in 2001 (n = 283) (Study I). The non-responders (29.2%) were older (82.5 vs. 79.1 years, $p < 0.001$), their MMSE scores were lower (25.5 vs. 26.6, $p < 0.001$), the Charlson comorbidity index was higher (2.7 vs. 2.3, $p = 0.010$), and they were more often females than the responders.

The range of WTL in years in Study I was wide. Only 3% of the males and 7% of the females reported no WTL. The responses were divided into three groups according to WTL in years. Of the respondents, 26.1% (n = 74) wished to live for less than five years (mean 2.3 years), 55.8% (n = 158) reported a WTL of 5–10 years (mean 7.9 years), and 18.0% (n = 51) wished to live beyond ten years (mean 17.6 years).

The predictive value of WTL as regards mortality was assessed during a ten-year follow-up period. The mortality rate was 68.9% among those with a WTL of less than five years, 45.6% in the WTL group of 5–10 years, and 33.3% among those with a WTL longer than 10 years (Figure 5:1). Differences between the groups

in Kaplan–Meier survival curves were tested by using the log-rank test ($p < 0.001$). Half of all the respondents had died by January 2010. The causes of death were similar in all groups; 57% died of cardiovascular disease, and 14% of cancer.

After adjusting for age, gender, education, comorbidities, smoking, MMSE scores and depressive feelings, the hazard ratios (HRs) for mortality in Cox regression analysis were significantly lower in the 5–10-year WTL group (HR 0.67, 95% CI 0.46–0.99, $p = 0.047$) and the > 10-year WTL group (HR 0.50, 95% CI 0.27–0.91, $p = 0.024$), compared with the < 5-year WTL group. In further analysis with WTL as a continuous variable, the findings in an adjusted Cox regression analysis were similar: each extra year that the participants reported as their WTL reduced their mortality (HR 0.95, 95 CI 0.91–0.99, $p = 0.0059$) (Figure 5:2). Thus, WTL is a strong predictor of survival irrespective of age, gender and comorbidities.

Figure 5:1. Study I: Kaplan–Meier survival curves in days during a 10-year follow-up period in three study groups (group 1: will-to-live < 5 years; group 2: will-to-live 5–10 years; group 3: will-to-live > 10 years). Differences between the groups were assessed by using the log-rank test ($p < 0.001$). Reproduced with permission from Karppinen et al. 2013

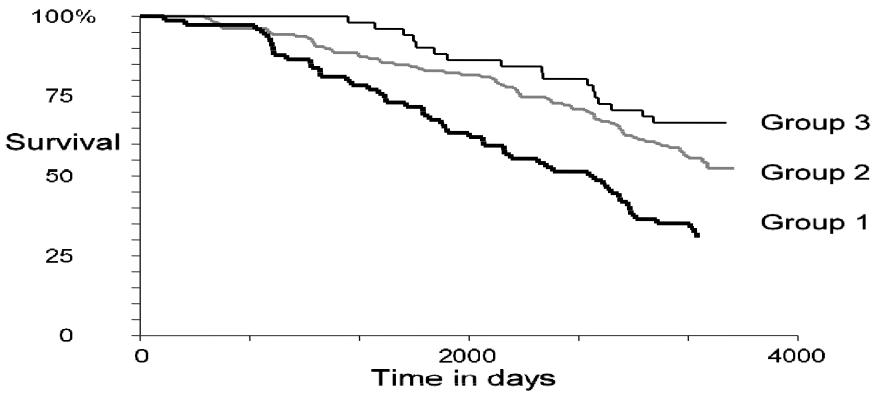
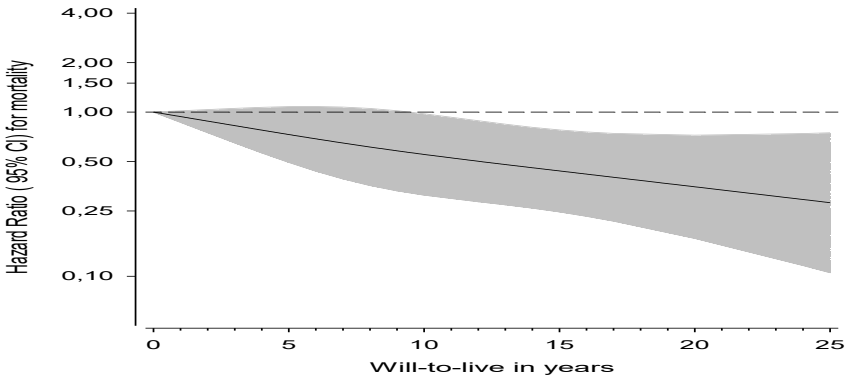


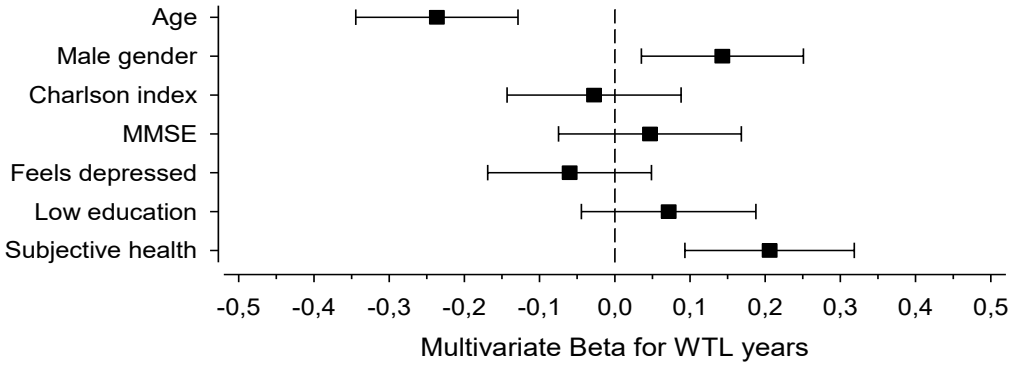
Figure 5:2 Relationship between WTL and mortality during a ten-year follow-up period. Hazard ratios with 95% CI (grey area) (adjusted for age).



Associations with willingness to live long (I)

The participants with the longest WTL were significantly younger, more often males, and more often reported good SRH. In multivariate regression analyses the Charlson comorbidity index did not predict WTL (Figure 5:3). There was no difference between the three WTL groups (WTL < 5 years, 5–10 years, or > 10 years) in cognition, depressive feelings, education or smoking history (Publication I, Table 1.)

Figure 5:3. Multivariate regression analysis of predictors of WTL in years. Standardized regression coefficients (Beta) with 95% CIs



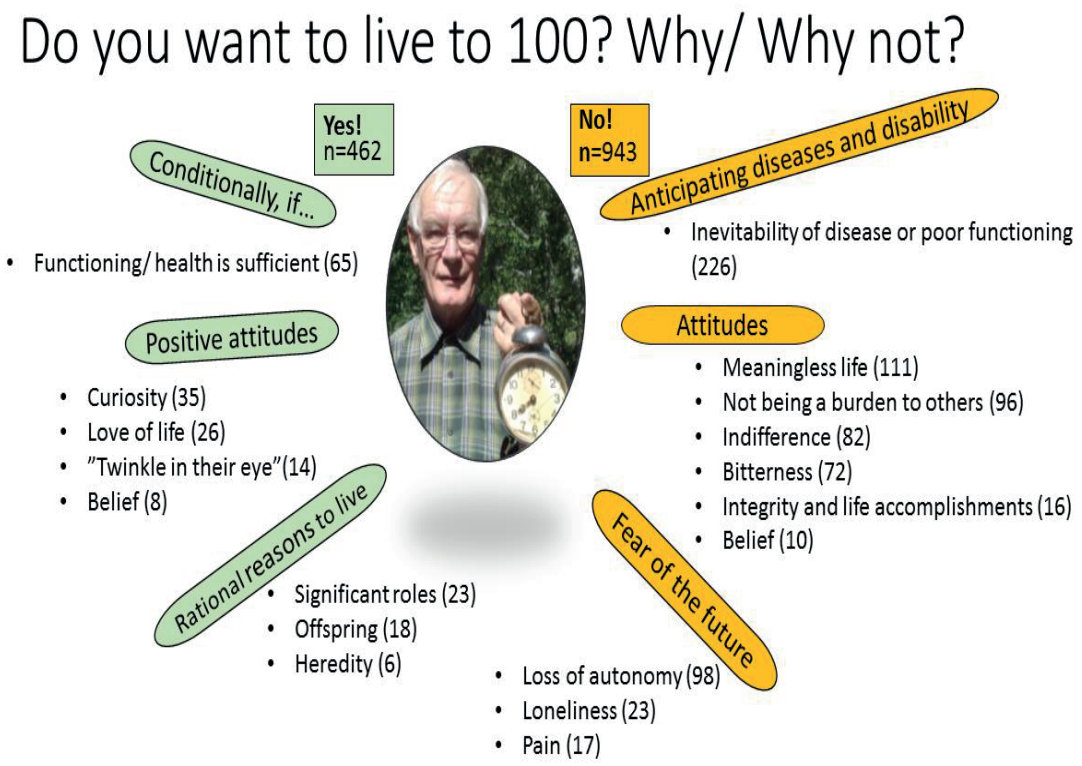
MMSE: Mini-mental state examination. Low education: ≤ 8 years of schooling. Subjective health (SRH): good health

5.2.2 To live or not extremely long? (II)

Longevity and willingness to live long was approached by asking "Do you want to live to be 100?" The respondents were also asked to tell us about the rationales for their response: Why?/Why not? The overall response rate was 74.3%. The non-respondents were older and more often females. As many as 32.9% (n = 462) of the responders were willing to become centenarians. Of 1405 participants, 613 provided reasons to live up to 100 (or not) in their own words.

These qualitative answers were categorized under emerging analytic themes (Fig. 5:4 and Publication II, Tables 2 and 3). Three themes for desire for long life could be detected: *conditional wishes*, *positive attitudes*, and *rational reasons to live*. The most common conditional wish was: "Yes, if I stay healthy". Among the positive attitudes, curiosity, love of life and "a twinkle in the eye" could be seen in responses. Many participants seemed to have significant roles or offspring as their rationales to live long. The reasons given by the participants who did not want to live extremely long lives were that they anticipated inevitable disease or poor functioning, or they had various attitudes, i.e. a meaningless life, being a burden to others, and indifferent or bitter thoughts. Many of them feared pain, loneliness, or, most commonly, loss of autonomy. Some people also shared the view that they had accomplished what they wanted in life.

Figure 5:4. Reasons to live or not to live to be 100: Emergent themes and categories with number of quotations in Study II



Associations with wishing to live up to 100 (II)

There was again an association between willingness to live long and male gender and/or good SRH (Table 5:2). The difference between genders was seen in all age groups, and this was more pronounced among the oldest-old. In this study, older age was associated with a wish to live to be 100 (Figure 5:5). The proportion of participants wanting to live up to 100 in different SRH groups is shown in Figure 5:6. Even among those feeling unhealthy, one in five wanted to live to be 100 years. Half of the respondents with very good SRH reported their willingness to reach 100. The overall satisfaction with health was prominent: prevalence of good SRH was high.

Table 5:2. Characteristics of participants wanting to live or not wanting to live up to 100 years (Study II)

	Do you want to live to be 100?		
	Yes (n = 462)	No (n = 943)	P-Value
Mean age, (range 75–96) years (SD)	84.6 (6.6)	83.2 (6.1)	< 0.001
Male gender, % (n)	38.7 (179)	26.6 (251)	< 0.001
Married, % (n)	36.8 (170)	32.8 (309)	0.13
Education < 8 years, % (n)	38.8 (177)	36.3 (339)	0.35
Good self-rated health % (n)	79.0 (365)	69.1 (652)	< 0.001
Charlson index, mean (SD)	2.0 (1.9)	2.2 (2.1)	0.080
Mean number of drugs (SD)	5.8 (5.5)	6.1 (5.9)	0.055

SD = standard deviation

Figure 5:5. Percentage of females vs. males wanting to live to be 100 years in different age groups

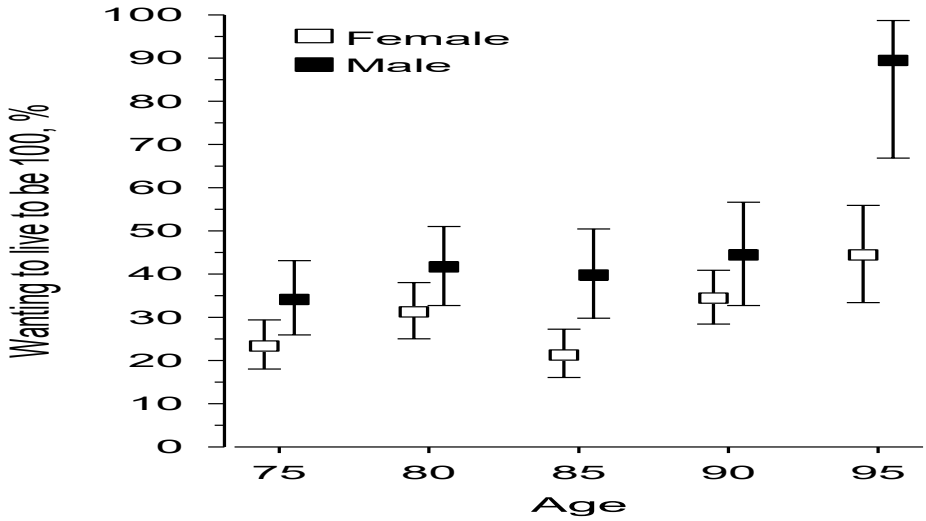
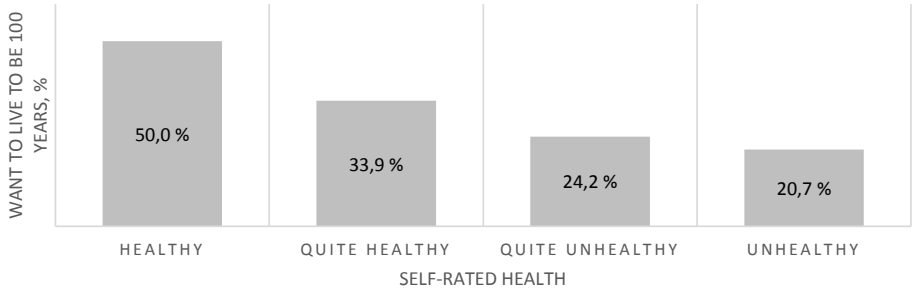


Figure 5:6. Willingness to live up to 100, grouped according to SRH in Study II



5.3 TIME TRENDS OVER 20 YEARS (III)

Self-reported disabilities, SRH, comorbidities and PWB were assessed at three time points (1989, 1999 and 2009) in cross-sectional independent cohorts in Study III. The numbers of respondents were 660, 2598 and 1637, and the response rates were 93%, 80% and 73%, respectively.

Table 5:3 below describes the characteristics, health and disabilities of each age group (unadjusted).

Standardized mortality ratios were determined at all three time points to assess representativeness of the samples. The SMR was 0.90 (95% CI 0.78–1.03) for the 1989 sample, whereas the corresponding ratios for the 1999 and 2009 samples were 0.71 (95% CI 0.64–0.76) and 0.60 (95% CI 0.54–0.66), indicating that the respondents represented fitter samples of their background population of the same age each decade.

5.3.1 Trends in health of participants (III)

Participants

There were significant demographic changes in successive cohorts over two decades (Table 5:3). The proportion of male respondents among the 80- and 85-year-olds increased significantly. There were fewer widowed respondents among 75-, 80- and 85-year-olds in later study years, and the educational status improved in all age cohorts except among the 95-year-olds.

Self-rated health improved in successive cohorts

SRH improved over 20 years when all age groups were combined together (adjusted for age). There were significant changes at certain ages: an increase among 80- and 85-year-olds, and a decrease among 90-year-olds. However, these analyses were unadjusted (Table 5:3). Generalized linear mixed models were used to find time trends. They were adjusted for gender, education and widowhood. In these analyses a significantly higher proportion in the group of 75–85-year-olds reported good SRH in the later study years ($p = 0.028$ for linearity for the study-year effect, $p < 0.001$ for the age effect, $p = 0.32$ for interactions; adjusted for gender, education and widowhood). Improving SRH in successive cohorts could not be verified in the group of 90- and 95-year-olds ($p = 0.057$ for the study-year effect, $p = 0.59$ for the age effect, $p = 0.63$ for interactions; adjusted for gender, education and widowhood).

Increase in comorbidities

Comorbidities over 20 years were assessed by using the Charlson comorbidity index (Charlson et al. 1987). Comorbidities increased (Table 5:3). Generalized linear mixed models revealed an increase in comorbidities over 20 years among 75–85-year-olds ($p < 0.001$ for linearity for the study-year effect, $p < 0.001$ for the age effect, $p = 0.13$ for interactions; adjusted for gender, education and widowhood). There was no increase in comorbidities in the 90- and 95-year-old cohorts between 1999–2009 ($p = 0.55$ for the study-year effect, $p = 0.25$ for the age effect, $p = 0.15$ for interactions; adjusted for gender, education and widowhood).

Table 5:3. Characteristics, health and disabilities in a cohort study over 20 years; unadjusted (Study III)

	75-year-olds			p	80-year-olds			p	85-year-olds			p	90-year-olds		p	95-year-olds		p
	1989 (n=245)	1999 (n=733)	2009 (n=399)		1989 (n=220)	1999 (n=713)	2009 (n=393)		1989 (n=195)	1999 (n=576)	2009 (n=264)		1999 (n=395)	2009 (n=197)		1999 (n=59)	2009 (n=51)	
Characteristics																		
Males, %	28.6	35.5	35.8	0.11	27.3	30.3	37.2	0.018	23.6	23.1	28.4	0.24	22.5	22.8	0.93	28.8	25.5	0.70
Widowed, %	35.0	29.4	21.1	<0.001	46.4	44.3	30.8	<0.001	57.8	57.4	49.4	0.079	63.6	62.4	0.78	67.9	60.0	0.40
Education <8 years, %	71.9	51.6	35.8	<0.001	70.3	49.8	38.1	<0.001	81.1	56.8	33.0	<0.001	54.6	40.4	0.0013	52.7	42.0	0.27
Health																		
Good SRH, %	77.3	84.2	83.4	0.12	67.3	74.8	79.1	0.004	56.3	75.0	74.4	0.002	69.8	63.1	0.049	71.4	65.2	0.40
Charlson index, mean (SD)	1.3 (1.4)	1.7 (1.8)	1.5 (1.6)	0.17	1.5 (1.4)	2.1 (2.1)	1.9 (1.8)	0.34	1.4 (1.1)	2.3 (1.9)	2.1 (1.9)	0.009	2.5 (2.0)	2.3 (2.0)	0.10	2.1(1.8)	2.4(2.0)	0.46
PWB, mean	0.75	0.83	0.83	<0.001	0.74	0.78	0.81	<0.001	0.69	0.73	0.73	0.11	0.67	0.68	0.37	0.64	0.61	0.52
Disabilities																		
Does not go daily outdoors, %	8.8	9.7	12.7	0.09	15.5	16.7	21.0	0.06	38.3	24.8	34.5	0.93	43.9	49.6	0.11	56.3	73.0	0.02
Needs daily help, %	11.3	9.4	8.0	0.16	12.9	11.7	13.4	0.73	26.1	20.0	24.4	0.97	32.0	34.4	0.48	42.9	53.1	0.19
Needs help to get out of bed, %	2.1	1.4	1.0	0.28	2.3	2.6	1.6	0.45	6.4	3.2	2.0	0.01	2.8	3.3	0.69	4.7	9.5	0.25

SRH = self-rated health. PWB = psychological wellbeing, SD = standard deviation

Signs of improving psychological wellbeing

Mean PWB increased significantly among 75- and 80-year-olds over the study years (unadjusted) (Table 5:3). Adjusted generalized linear mixed models supported a trend of improving PWB among 75–85-year-olds between 1989–2009 ($p = 0.0055$ for linearity for the study-year effect, $p < 0.001$ for the age effect, $p = 0.39$ for interactions; adjusted for gender, education and widowhood). In the group of 90- and 95-year-olds, there was no difference in PWB between study years 1999 and 2009 ($p = 0.49$ for the study-year effect, $p = 0.040$ for the age effect, $p = 0.50$ for interactions; adjusted for gender, education and widowhood). Figure 5:7 illustrates PWB declining with age but improving in cohorts of the same ages over two or three time points. The six items of PWB are illustrated in Figure 5:8 below. There was a gender difference: male respondents rated their PWB higher than females did at the same age.

Figure 5:7. Mean PWB (psychological wellbeing) in three cohorts and various age groups

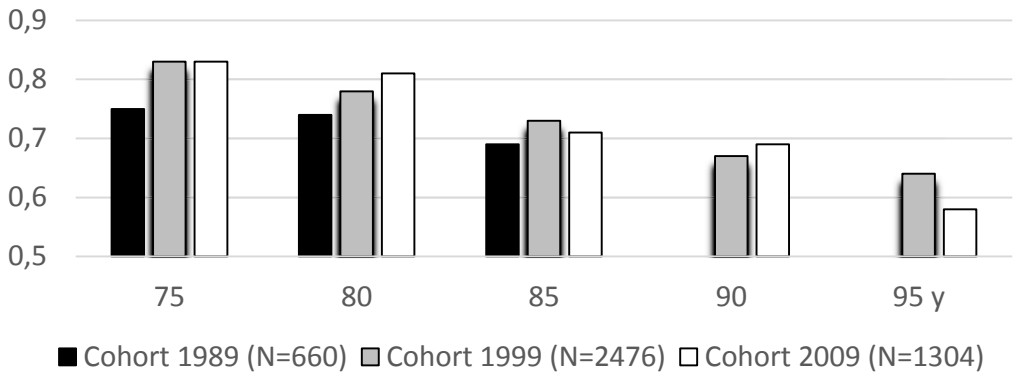
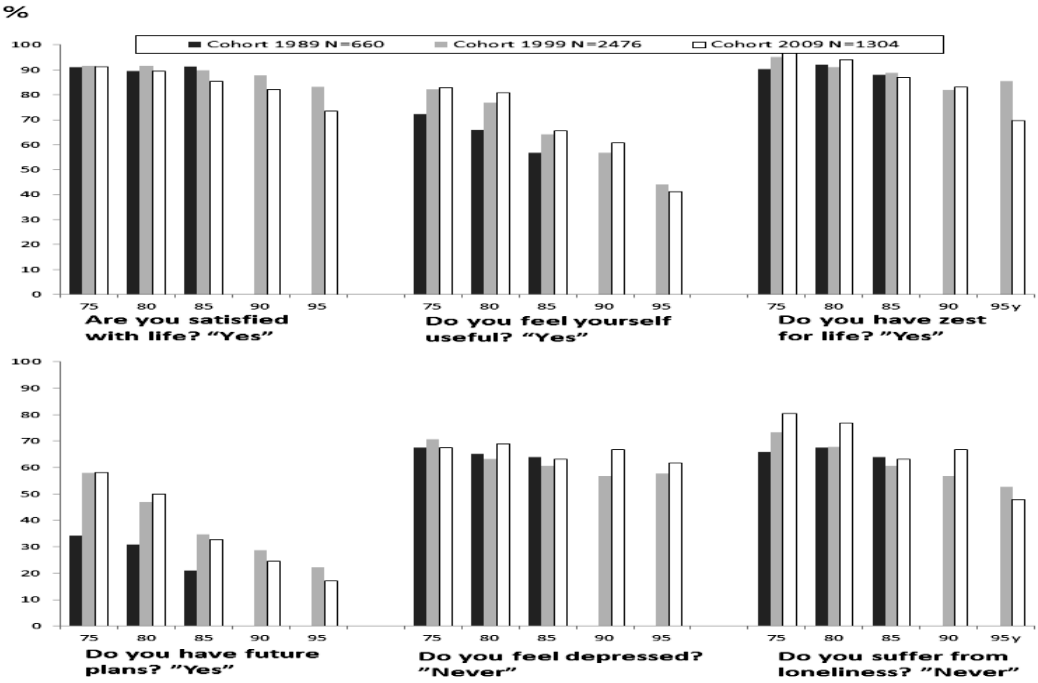


Figure 5:8. The six items of the PWB scale at three time points at different ages. Percentages of responses



5.3.2 End of improving physical functioning? (III)

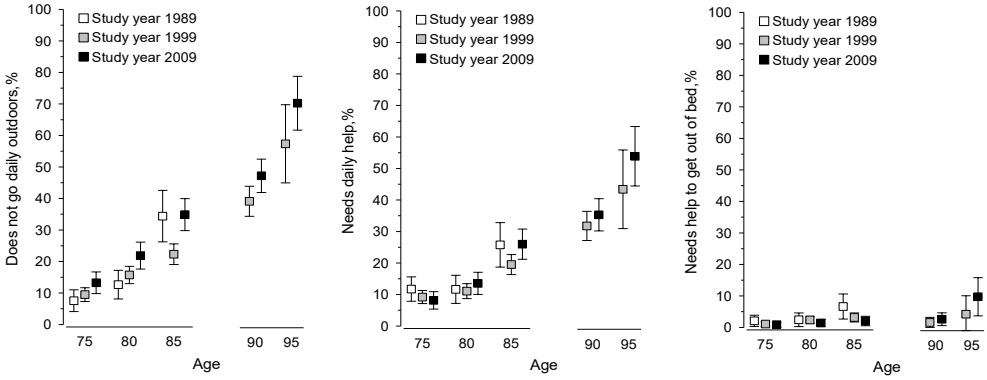
At all study points, the participants were invited to report whether they go outdoors on a daily basis, whether they need daily help from others, and whether they need help to get out of bed. Some improvements were seen up to 1999, but a levelling-off was detected after that. (See Table 5:3 above and Figure 5:9 below.)

In generalized linear mixed models smaller proportions of older people of the same ages reported going outdoors on a daily basis in the later years, both among 75–85-year-olds ($p < 0.001$ for linearity for the study-year effect, $p < 0.001$ for the age effect, $p = 0.043$ for interactions; adjusted for gender, education and widowhood) and among 90- and 95-year-olds ($p = 0.030$ for the study-year effect, $p < 0.001$ for the age effect, $p = 0.57$ for interactions; adjusted for gender, education and widowhood). In contrast, no time trend was discovered concerning the need of daily help. There was only an age effect in both age

groups (75–85-year-olds : p = 0.84 for linearity for the study-year effect, p < 0.001 for the age effect, p = 0.30 for interactions; adjusted for gender, education and widowhood, and similarly among 90- and 95-year-olds: p = 0.14 for the study-year effect, p < 0.001 for the age effect, p = 0.56 for interactions; adjusted for gender, education and widowhood).

Not many people needed help to get out of bed. The generalized linear mixed models revealed improvement in the group of 75–85-year-olds (p = 0.022 for linearity for the study-year effect, p = 0.0012 for the age effect, p = 0.82 for interactions; adjusted for gender, education and widowhood), but in the group of 90- and 95-year-olds there was only an age effect between the two study years 1999 and 2009 (p = 0.18 for the study-year effect, p = 0.019 for the age effect, p = 0.56 for interactions; adjusted for gender, education and widowhood).

Figure 5:9. Three items of self-reported disability with 95% confidence intervals (unadjusted)



5.4 LIVING WILLS AND REALITY AT THE END OF LIFE (IV)

5.4.1 Living will without influence on intensity of care (IV)

Living wills among Finns usually describe a person´s willingness to forgo heavy procedures. For Study IV, the study nurse interviewed participants of the DEBATE study (n = 378), carried out in 2001. She asked, among other things, whether the participant had signed a LW document. During a 10-year follow-up period, 207 of them died (54.8%), the mean age of the deceased being 82.1 years at baseline. Thirty (14.5%) of these deceased participants

of Study IV had reported having a LW at baseline. A difference at baseline between the groups with a LW (n = 30) and those without (n = 177) was the reported health status: SRH was more often good in those participants who had a documented LW at baseline (83.3% vs. 54.2%, p = 0.0037). Differences in age, gender, education, marital status, cognition or comorbidities were not seen (Publication IV, Table 1).

There were no differences in the intensity of received care between the study groups at the close of life: half of the participants in both groups experienced an acute or even aggressive treatment episode before death. Almost one in ten had been resuscitated or had undergone a resuscitation attempt during the last days of life (10.0% vs. 8.5%; p = 0.78). Only 4% of the participants had been admitted to an intensive care unit. Only one-third of the decedents had had a conservative and palliative treatment plan. Causes of death were similar in both groups.

5.4.2 Living will and site of death preferably at home (IV)

Site of death and its association with LW was not among the primarily explored items in this study. Judging by the death certificates, however, most of the oldest-old were living at home one year before they died. Furthermore, nearly without exception all participants had stayed at the place of death for either less than three months or more than a year (unpublished data). The event history, which has to be written on a Finnish death certificate, was informative in most cases.

Most participants died in acute hospitals, both among those with and without a LW at baseline (76.7 % vs. 76.8 %, p = 0.87), and hospice deaths were rare (0% vs. 2.8%, respectively). Death occurred significantly more often at home among those who had completed a LW at baseline (16.7% vs. 5.6%, p = 0.031).

Additionally, differences in dying processes emerged from the death certificates. Half of the participants with a prior LW died within a period of less than a week, which was the case in only a quarter of the decedents without a prior LW (50.0% vs. 27.1 %, p = 0.013).

6 DISCUSSION

6.1 RESULTS IN BRIEF

This thesis explores thoughts and self-perceptions of older adults and the oldest-old. Participants were community-dwelling older people aged 75–96 at baseline in 1989, 1999 and 2009 in Helsinki. The data comprises self-assessments, perceptions of getting old, preferences towards end of life, plus data from death certificates and some registry data.

Wishes for a long life were explored in Studies I and II. In a 10-year follow-up study (Study I), WTL was a predictor of survival: participants who wished to live longer survived longer, regardless of their physical health at the time their desire was expressed, even when adjusted for several confounding variables. In Study II, one-third of 1405 participants wished to live up to 100, more often the oldest ones, males, and those with good SRH. Their rationales to live long revealed optimistic or curious attitudes and significant roles in life, whereas reasons not to live extremely long were reported in terms of assumptions that a long life would lead to obvious disabilities. Conditional thoughts were the most common: *If* I stay healthy. The participants were also reluctant to become a burden to others, or they feared loss of autonomy.

Cohort trends in health and functioning of older people were investigated in the third study (Study III). In the cohort study covering 20 years, morbidity was increasing in old age, but self-ratings in health and psychological domains (SRH and PWB) were still suggesting improving trends. On the other hand, some daily activities in physical functioning (needs daily help from another, goes outdoors on a daily basis, needs help to get out of bed) among older people improved up to 1999 but levelled off thereafter.

Study IV concerned what happens at the close of life among those older people who described their thoughts about dying earlier at baseline. Death certificates of 207 participants were analysed to find associations with a living will and end-of-life care in this retrospective study. There were no differences between the groups with and without a

prior LW in receiving active or even aggressive treatments, or dying in hospital. However, older people with a LW document at baseline in 2001 died significantly more often at home, and their dying process was more often less than a week than it was among those without a LW.

6.2 STRENGTHS AND LIMITATIONS

Strengths of the study

The thoughts of older people and the oldest-old living in their homes in urban Finland were explored for this thesis. It is population-based, and the samples were retrieved randomly. Population register data in Finland are comprehensive and accessible for research. Community-dwelling older people are most likely to make their own choices about themselves and about use of social and health services, especially in primary care. The samples in these studies are well representative of the population that lead their so-called 3rd or 4th lives possibly helping their offspring or other older people. This is thus representative of a fit proportion of the older and oldest population. The low prevalence of dementia is likely to strengthen the reliability of responses, and the educational level does not lead to any relevant bias. Certain differences between the oldest-old and older adults exist, as is known from previous research (Christensen et al. 2009, Seeman et al. 2010, Sarkeala et al. 2011, Christensen et al. 2013). Here, the age-range was wide, and the oldest-old could be analysed accordingly. Thus, this research adds insight to deeper understanding of the oldest-old, among whom research is still scarce.

The inquiries and structures of the questionnaires were identical during the 20 years of this research. The respondent had the possibility to fill in the form at his/her own pace, and the questions were easy to answer. In addition, the participants were thoroughly examined and interviewed for Studies I and IV (DEBATE) by an experienced study nurse and geriatrician. The discussions were conducted in a peaceful environment. Furthermore, the participants in Studies I and IV were cardiovascular patients and thus more aware of a

possible imminent death and therefore willing to talk about it. They may have had well-developed thoughts about the last years of their lives.

There are other strengths as well. The response rate was high, which is common among Nordic people. The 10-year follow-up period in Study I was long enough for the purpose of this study. Three time points over 20 years in Study III were regarded as appropriate in order to explore time trends in the older population. Last, Finnish death certificates produced ample information for use in Study IV. All death certificates, after being written and signed by a clinician, are controlled by the county coroner.

Limitations of the study

Although this was a population-based study with random samples of older people, the selection of respondents was selective, thus not being representative of older Finns. At baseline, all institutionalized older people were excluded, and all participants lived in the city of Helsinki. There were some differences in demographic data between the study participants and the non-respondents. The non-respondents were older in Studies I and II. They had more comorbidities in Study I, and males were more likely to fill in and return the questionnaire in Study II. Lower mortality of the cohort participants in Study III in a 4-year follow-up period provide convincing evidence that the study participants survived longer than older adults of the same age and gender at that time in Finland. Absence of the non-respondents and its possible influence on the results is discussed further below (Section 6.3; Methodological considerations).

In addition to the above, only a highly selective proportion of people respond to the most difficult inquiries concerning death and dying. This was especially the case in Study II, where rationales to live or not to live to be 100 years were inquired about in a questionnaire, among other questions. Only 613 of the 1405 participants explained their wishes in their own words. Owing to the nature of postal surveys, the participants could not be thoroughly examined for Studies II and III. Performing a traditional qualitative in-depth interview study might have given a deeper view into older people's thoughts.

Response rates declined over the study years, from 93% in 1989, to 80% in 1999 and to 73% in 2009, which is a common global trend (Moe & Hagen 2011). Furthermore, the number of participants was not the same in different cohorts in Study III. The cohorts in 1989 were small, and 90- and 95-year-olds were completely missing. Also, in 1999 and 2009 the percentages of participants in these oldest age groups were low, thus reducing the power of the study.

6.3 METHODOLOGICAL CONSIDERATIONS

6.3.1 Participants

Population-based random samples of older people from the Population Information System of Finland enable researchers to extract information on community-dwelling people who are the most likely to take part in surveys. The selection bias is discussed above (Section 6.2). The participants in the DEBATE study (Studies I and IV) were highly selected, because all participants had been diagnosed with a major cardiovascular disease. Although they were cardiovascular patients, they still represented the fittest proportion of the population, judging by their mortality data (Strandberg et al. 2006). The mortality rate among participants in Studies II and III was also relatively low, compared with that in the background population. The standardized mortality ratio (SMR) indicates that approximately 10% less of the respondents died during the four-year follow-up period than would have been expected in their background population in 1989. The mortality rate in the cohorts in 1999 was 29% lower, and in 2009 40% lower.

The least well-educated participants were in Studies I and IV, where each of them had a major cardiovascular disease, but who were comprehensively examined and interviewed by a study nurse and a physician. On the other hand, more educated participants were found in Studies II and III, for which the data-gathering method was a postal questionnaire. A gender difference among respondents was evident but not surprising: the proportion of females is higher than that of males in most surveys among older people in these age

groups. However, the proportion of male respondents increased over the study period. Decreasing number of widowed respondents may reflect longer life expectancies, especially of men.

The results might have been slightly modified if all non-respondents could have been included in the studies. In Study I, the importance of WTL might have been strengthened, because the non-respondents had more comorbid conditions and they were older than the respondents. In Study II the relevance of the non-respondents is more complicated: the oldest respondents were more willing to live up to 100 years of age than the younger ones, and the non-respondents were older than the respondents. As for Study III, response rates decreased over time (1989-2009). This probably weakens the suggested increases in impaired functioning in later born cohorts. In Study IV non-response is of minor relevance because in this retrospective study only the respondents with a prior opinion about EOL issues were eligible as participants.

6.3.2 Measures

The demographic items were simple and unambiguous, such as gender, marital status, education and lifestyle. The Charlson index was developed for research purposes and is a widely-used and validated measure for life-threatening comorbidities (Charlson et al. 1987). The fundamental importance of SRH has been established in research (Ferraro & Wilkinson 2015). The MMSE is the only measure of health in this thesis that cannot be self-assessed. It reflects the level of cognition both in geriatric research and diagnostics, and follow-up of cognitive decline in a clinical setting (Folstein et al. 1975).

The topics in this study are easy to understand both among health-care providers and lay people. However, the domains that were studied are not unambiguous by definition, and different people see them in different ways. This may lead to limitations in choosing appropriate measures and interpreting the results. As a new measure, WTL (in years) was

introduced in Study I. The question was easy to understand, and the results were promising. As far as I know, only Lawton (1999) has asked a similar question, concerning "years of desired life".

Psychological wellbeing is a six-item measure that covers six dimensions. These six questions show good test-retest reliability (Savikko et al. 2006) and significant prognostic validity as regards mortality (Pitkälä et al. 2004). The three items used to assess limitations or disabilities (not going out on a daily basis, needing daily help, needing help to get out of bed) are common, and they were easy to answer, but not sufficient alone to allow the drawing of clear conclusions about significant cohort trends in physical functioning (Valvanne 1992).

6.3.3 Quantitative methods

Self-evident phenomena need to be tested. This was the case in research questioning concerning WTL (Study I), wishes concerning living to extreme ages (Study II), and realization of a living will (Study IV). Precise numbers, proportions and risks put the results into perspective, thus allowing other international researchers to compare demographic data, prevalence rates or results with their own data.

Data was gathered only via postal questionnaires in Studies II and III. Postal questionnaires represent a commonly used survey method in epidemiological studies. Reporting of results has to be tempered by the limitations of postal surveys. Responses may vary according to how they have been inquired about (Li et al. 2010). The situations for filling in the forms vary between respondents: how much time taken pondering do they spend and do the responses reflect their own opinions? However, this method makes it possible to investigate large samples.

Self-assessments concerning physical functioning or diagnosed diseases in a lengthy questionnaire do not always reflect reality. Respondents may overestimate their abilities

in functioning (Jylhä 2006). Not all respondents may remember or recognize all the diseases they might have (Parker & Thorslund 2007). On the other hand, currently there is more emphasis on increasing the use of self-assessments both in research and clinical use (Steptoe et al. 2015). In addition, self-reported estimates should be reliable at a population level and, thus, cohorts are comparable.

6.3.4 Qualitative methods

Qualitative methods (especially thematic content analyses) for this thesis were applied to track perceptions of the oldest-old regarding living up to 100 years (Study II), and to explore the last year and end of life of cardiovascular patients (Study IV). These methods enhance understanding of ageing, living with chronic conditions and nearing death, as experienced by the participants. There is a large body of qualitative research in the field of ageing by social scientists and psychologists. Less has been published by clinicians who face ageing men and women in their practices.

Qualitative research can provide insight into "taken-for-granted" knowledge that those working with older people apply (Godfrey 2015). Especially as regards research, new perspectives towards life and death arise, enabled by qualitative methods, where participants themselves provide the data. However, open-ended questions in a questionnaire can be regarded as a methodological limitation of the study, in comparison with carrying out semi-structured or open deep interviews with grounded theory analysis. Regardless of this limitation, all qualitative approaches may raise new ideas to improve the lives of older people in greying societies.

6.4 INTERPRETATION OF THE RESULTS

6.4.1 Will-to-live as a predictor of survival (I) and wishes concerning length of life (I, II)

Will-to-live (I)

The participants with cardiovascular disease in Study I reported a strong WTL: three out of four (74%) wished to live at least five years and one out of five (18%) wished to survive over 10 years. This is in line with a survey among younger, healthy and wealthy American community-dwellers: half of the respondents (70+) wished to survive for 6–20 years and one third even beyond that, when they were asked to express *years of desired life* (Lawton et al. 1999). In both studies, the percentage of older adults without any WTL was less than 5%.

Expressed WTL in years predicted survival even after adjusting for age, gender, educational level, comorbidities, smoking habits, cognition and depressive feelings. This indicates that WTL is an independent predictor of survival, which was also discovered in an Israeli sample (Carmel et al. 2007). However, unlike in Israel, where the researchers detected no predictive value as regards survival among males, in Study I the predictive value was equal in both genders. Furthermore, in recent publications WTL has been demonstrated to have a reciprocal relationship to the modern concept of *successful ageing*. In a one-year follow-up study among over 1000 community-dwelling older Israelis, WTL predicted both subjective and objective successful ageing after one year, and vice versa, but the influence of WTL on subjective successful ageing was stronger than the reverse effect. (Shrira et al. 2018.)

There are also contradictory results: whereas in Study I WTL showed no associations with depressive feelings, in a recent study by Carmel et al. an inverse association with depression seemed to be prevalent (Carmel 2017). In other studies (Carmel et al. 2013) education has had a role, in contrast to the results in Study I. Cognition was not associated with WTL, which may be due to the small number of respondents, high MMSE scores

among the respondents, and the fact that the non-respondents to the WTL question scored significantly lower in the MMSE than the respondents (25.5 versus 26.6).

Since Study I, Carmel has been working for an appropriate measure for WTL. She defined the domains for a new scale that is easy to use (Carmel 2017). The scale is feasible in research, but too long for clinical practice. The simple inquiry about WTL in years in Study I is practical but not thoroughly validated. WTL in years cannot be taken as a stable measure. Societally transmitted negative attitudes to ageing may affect wishes to live long. (Levy et al. 1999, Marques et al. 2014, Bowen & Skirbekk 2016, Kalfoss 2016.) WTL as an independent and personal concept was easily accepted by all geriatricians in a focus-group survey in the USA and Israel and was suggested to be taught to all students in health care (Damron Rodriguez & Carmel 2014).

Do you wish to live up to 100 years? (II)

One-third of the sample wished to live up to 100, which is in line with a study among older men in Finland (Huohvanainen et al. 2012). In an American study none of the 70–97-year-olds wished to live up to 100 (Cicirelli 2006), whereas more than 50% of Portuguese 60–90-year-olds were willing to reach centenarian status recently (Ribeiro et al. 2018). Therefore, more questions arise: do cultural or geographical aspects have a strong effect? Have attitudes towards ageing changed towards a more positive direction over a decade? Or do the results differ because the inquiry about wishing to live up to 100 years has been posed in different situations in various surveys? Differences in proportions of non-respondents may have an impact on the conflicting results.

In this study, male gender and older age was associated with a wish to live to be 100. This is somewhat surprising, knowing that expected survival is shorter among older and male participants. This association is in contrast to the WTL results of Study I, where older age was associated with a shorter WTL. An explanation for this may lie in a phenomenon that was reported at the turn of the millennium: older people seemed to be able to postpone their death for the opportunity to live into the 21st century, judging by the

overrepresentation of deaths in January 2000, without any other plausible explanations (Sinard 2001). This may also be in line with a persistent and lifelong zest for life, reported in centenarian studies: I am ready to go – but not today or tomorrow (Jopp et al. 2016).

6.4.2 Reasons to live or not to extremely old age (II)

The reasons given by the oldest-old themselves to live up to 100 are in line with those in a younger sample where an active and healthy life with plans and wishes emerged as the most important constructs of good ageing (Huijg et al. 2017). But unlike in that Dutch study, the respondents in this Finnish study did not put value on travelling or other activities.

The given rationales are also in line with studies of the oldest-old (95–101 years) in Cambridge. They were not concerned about death itself, but merely about the dying process with possible pain, or the nearest ones who would be left behind. As in Study II, the participants were longing for quality of life, painless death, and they did not want to be a nuisance. (Fleming et al. 2016.)

Warmoth et al. explored older people´s perceptions of ageing in a recent systematic review (2016). Even now there are not enough high-quality studies that combine self-perceptions with health and functioning. Nonetheless, it became clear that older people´s ageing perceptions are associated with their health and functioning. (Warmoth et al. 2016.)

6.4.3 Time trends among older people over two decades (III)

Participants

In this cohort study of older people aged 75/ 80/ 85/ 90 or 95 years, some time trends were seen in health and wellbeing. There were also some significant demographic changes in cohorts. The proportion of male respondents increased among 80- and 85-year-olds and educational status improved among 75–90-year-olds, which has also been reported elsewhere (Moe & Hagen 2011, Laditka & Laditka 2014, Martin & Schoeni 2014). Widowhood decreased over 20 years. This reflects increasing life expectancies, especially among men.

Response rates also decreased over the years. It may partially be explained by the change in the definition of institutionalization in Finland. In 1989, 1999 and 2009 in Helsinki, the proportions of the institutionalized 75+ population were 16.0%, 13.7% and 6.0%, respectively. The names of most nursing homes were changed to "assisted living facilities" over these two decades, meaning that many nursing home-dwellers in 1989 would be regarded as community-dwellers today. However, it was the fit part of the older population who responded in this study, rather than those who would need round-the-clock care. Other reasons may thus explain this reduction better: decreasing response rates have been reported worldwide (Moe & Hagen 2011).

Owing to the small number of 90- and 95-year-olds, changes between 1999 and 2009 could not be detected in this oldest group. These oldest-old were not approached in 1989 sample.

Self-rated health improved in successive cohorts

SRH improved over 20 years when all age groups were analysed together (unadjusted data). Social engagement or improved PWB may contribute to these findings. When analysed in two groups again, there was a trend towards improvement and an age effect in 75–85-year-olds. In turn, no change was verified in 90- and 95-year-olds. Neither was there an age effect. This is in line with a few other studies suggesting improving SRH among younger old but not among nonagenarians (Doblhammer & Kytir 2001). Researchers in Thailand (Karcharnubarn et al. 2013) and earlier in the UK and USA have also reported improvement among the 80+ population (Dening et al. 1998, Martin et al. 2007). Some data contrary to that in Study III can be found as well (Parker & Thorslund 2007, Jylhä et al. 2013). It can be assumed that no trend could be found for 90- and 95-year-olds in Study III, because of the small number of 90- and 95-year-olds and the short time period, only one decade. Some other explanations can be considered as well. In many cohort studies, the association with SRH seems to decrease with increasing age (Doblhammer & Kytir 2001). There was no age effect in Study III among the oldest group, as in the Vitality 90+ study (Jylhä et al. 2013). Regardless of how SRH has been inquired, many of the oldest-old tend to compare themselves with other persons of their age, thus rating their own health as

being relatively good. However, ratings of excellent health have declined (Martin et al. 2007, Jylhä et al. 2013). In Study III "good health" consisted of both "healthy" and "quite healthy".

Increase in comorbidities up to 1999

The Charlson index increased over 20 years in the total population in Study III. However, a significant increase was seen only during the first decade until 1999. No further increase was detected after that. Increases in comorbid conditions up to 2000 have been verified in other studies as well (Crimmins 2004, Parker & Thorslund 2007, Christensen et al. 2009, Crimmins & Beltrán-Sánchez 2011, Galenkamp et al. 2012, Hoeymans et al. 2012). Diagnostic work among the oldest-old increased in the 1980s and 1990s, more medical treatments for dementia and osteoporosis came into use, and the role of secondary prevention was reinforced in primary care. Research after 2000 among nonagenarians has been scarce or not reported so far. Our results are in line with those of the Vitality90+ study, where there were no time trends in any of the diseases that were explored, nor in multimorbidity between 2001 and 2010. Similarly, multimorbidity showed no association with age among the 90+ population in Vitality 90+, which was the case for our 90- and 95-year-olds as well. (Jylhä et al. 2013.) Instead, our results showed an increasing trend of comorbidities in the group of 75–85-year-olds, as well as an age effect.

Signs of improving psychological wellbeing

There was a time trend in improvement of PWB over 20 years, especially among 75- and 80-year-olds. Using generalized linear mixed models, improvements were detected only in the group of 75–85-year-olds. PWB decreased with age. As far as I know, there are no other available studies about trends in PWB among older people.

This favourable finding is probably due to higher educational levels in later-born cohorts and a decline in the percentage of widowed participants. Another biasing factor may be the change in the SMR over the study years: the later-born cohorts may be more representative of the privileged proportion of the oldest-old. Social contacts or engagement in life may also be possible contributing factors: Among the six items of the

PWB scale (satisfied with life, feeling depressed, suffering from loneliness, feeling useful, having zest for life and having future plans), striking improvements can be seen in "*feeling useful*" and "*having future plans*". Having plans and engagement in life are strongly associated with "*life satisfaction"* among older people in recent studies (Hicks & Siedlecki 2017). Some epidemiological data suggest that the life-course perspective of psychological health is different in different countries: evaluative wellbeing such as life satisfaction is U-shaped in western countries, with the poorest wellbeing in middle age, whereas in the former Soviet Union, Eastern Europe and Latin America life satisfaction continues to decrease with age (Blanchflower & Oswald 2008, Steptoe et al. 2015). Whether changes in Finnish society have any influence on improving PWB in this respect cannot be judged by this research.

"Loneliness" did not seem to change remarkably over 20 years. Figure 5:8 illustrates that the prevalence of not suffering from loneliness was at the same level in all age groups. One could claim that loneliness has even improved in the oldest-old age groups. This is contradictory to previous research in two ways. First, other studies suggest an increasing prevalence of loneliness with age (Jylhä 2004, De Jong Gierveld et al. 2016). Second, a 28-year follow-up study, TamELSA, suggested an increase in loneliness especially among the oldest-old (Jylhä 2004, Aartsen & Jylhä 2011). Parallel outcomes have been reported in different countries: between age-group waves, loneliness among older people is increasing (Cohen-Mansfield et al. 2009, Dahlberg et al. 2015). Again, the participants of this study were not representative of all older people in Finland.

A gender difference in PWB scores was obvious. More than four out of five 75-year-old male respondents scored at least 0.8, which is regarded as good PWB (PWB scale 0–1). Even among 95-year-old male respondents two out of five reported good PWB. Female respondents scored less than males in all age groups. This is interesting, because gender differences in single items of this PWB scale have been somewhat different in research. Males usually score better in SRH, anxiety and loneliness. A reduction in the social network predisposes males to loneliness, but females seem to lead more meaningful lives than

males. (Deeming 2013, Dahlberg et al. 2015, Carmel et al. 2017.) Nearly all respondents had experienced war, which usually increases depressive symptoms, especially among women (Carmel et al. 2017).

End of improving physical functioning?

There seemed to be improvements in all three items concerning disability or limitation, especially among 85-year-olds from 1989 to 1999, which is in line with studies from other Western countries (Manton & Gu 2001, Freedman et al. 2002, Crimmins 2004, Sulander et al. 2006). After that and towards study year 2009 further improvements cannot be seen. This analysis suggests a levelling-off after decades of improvements in functioning. In some respects, the limitations are even increasing in later-born cohorts of the old and the oldest-old, suggesting downward trends. This agrees with studies in other countries. In Norway and Sweden, functioning in older cohorts was improving until the mid-1990s before levelling-off among older adults under 80 years of age. Similar changes suggesting worse functioning among 80+ adults started at the beginning of the 2000s (Parker et al. 2008, Moe & Hagen 2011, Jylhä et al. 2013). In the USA, signs of deterioration have been reported; at first among the middle-aged and later in all age groups, including older people (Freedman et al. 2002). On the other hand, cohort comparisons among community-dwelling people aged 80+ in Thailand still suggest improvements in mobility at the beginning of the 21st century (Karcharnubarn et al. 2013). The worrisome trend is worldwide but was first seen in Western countries (Parker & Thorslund 2007, Christensen et al. 2009, Seeman et al. 2010, Cambois et al. 2013). As far as I know, time trends concerning these three specific items in other studies cannot be found, for comparison with Study III.

Smaller proportions of older people of the same ages reported going outdoors on a daily basis in the later years, both among 75–85-year-olds and among 90–95-year-olds, adjusted for gender, education and widowhood. The results may be even more worrisome for three reasons. Firstly, the respondents of 1999 represented a significantly fitter selection of older

people of their age in Helsinki than were the respondents in 1989. The difference between respondents in 2009 compared with those in 1999 is even more distinct, judging by the SMRs. Secondly, the weather conditions in Finland often change daily routines and possibilities to go outdoors. Considering this, the latest questionnaires were mailed in summer in 2009, when the percentage of "not going out on a daily basis" responses was the biggest. The questionnaires were mailed late in the autumn in 1989 and during winter in 1999. Thirdly, over the study years, there have been attempts to help people go outdoors: communities have provided older people with more mobility aids if needed, elevators have been built in many old houses, and volunteers have been trained to help older people. Knowing these facts, the trend staying inside the house is more alarming.

The generalized linear mixed-models suggest trends

This study suggests time trends among the fit share of community-dwelling older people aged 75–95 years. Previous research, including institutionalized people, has revealed deteriorations in physical functioning (Jylhä et al. 2013). Also, future community-dwelling older Finns may be loaded with more physical limitations and disabilities. They may need more and different activities at home, if the trend of not going out on a daily basis continues. In turn, the old and the oldest-old seem to be more content with their health and life, judging by improving SRH and PWB. This can be partly explained by higher educational levels (Freedman & Martin 2006, Sulander et al. 2006, Laditka & Laditka 2014) and a lower proportion of widowed persons.

An age effect is evident in physical limitations, disabilities, SRH and PWB. Age has also been a major predictor in other studies (Sulander et al. 2003, Moe & Hagen 2011). However, the effect of age diminishes over time among the oldest-old as far as SRH or PWB are concerned. The oldest-old often rate their health and ADLs higher than expected. It is challenging to explain the results of Study III, where data was gathered via postal surveys and thus only self-perceptions could be used. Critical appraisal of cohort studies is difficult because of the various measures used, different definitions of concepts, non-comparable sampling of participants, and cultural issues (Freedman & Martin 2006). Study III is a

pioneer investigation as regards the exploration of both physical and psychological domains of health and wellbeing in the same study.

The lower mortality rate among participants compared with their background population (SMR < 1 in all cohorts, continuing to diminish each decade) enforces the pessimistic time trends and depresses all results suggesting improvements in later-born cohorts. The need for care will increase, not only because of the suggested trend towards increasing disabilities, but also because of a higher average age at death (Forma et al. 2009).

The concept of *Compression of morbidity* launched by Fries (1980) was an optimistic view of the future where age-related diseases will be better treated such that the time-span of disabilities and dependence will be shifted to an older age: the dependent period in life should be as long as it is now among younger people facing death. In the light of the results of the current work and other research, two other theories appear to be more relevant, i.e. Expansion of morbidity and Dynamic equilibrium. *Expansion of morbidity*, proposed by Gruenberg (1977) fits the current situation to some extent: morbidity among older people did indeed increase, but later increases were no longer detected. Another name for Gruenberg's theory was *Failures of success*. Survival has been extended successfully to very old ages, and the prevalence of multimorbidity has increased (Chen & Sloan 2015). However, increases have primarily been connected with more benign diseases, such as osteoarthritis. More severe diseases are better controlled now (e.g. coronary heart disease, or stroke). Manton´s theory of *Dynamic equilibrium* (1982) offers the opportunity to balance between severe disabilities and prevention, treatment and rehabilitation in this world where life expectancies are still increasing. Moreover, the finding of increasing PWB maintains the hope that regardless of severe disabilities the oldest-old may be content.

6.4.4 Living will, intensity of end-of-life care and site of death (IV)

The participants in Study IV were 207 deceased cardiovascular patients of the DEBATE study, who died during a 10-year follow-up period. At baseline 30 (14.5%) of them had reported having a LW. The prevalence of a LW was small but comparable to that in many

other surveys among older people (Hilden et al. 2004a, Hilden et al. 2004b). The discontinuation of unsuccessful treatments is required almost without exception in Finnish LWs, especially at the time when interviews for this thesis were conducted. Therefore, it can be assumed that participants with a LW wished to forgo heavy procedures if there was no hope of full recovery.

The data drawn from death certificates did not show any differences in active or aggressive treatments between those with a LW and those without one. Half of the decedents in both groups experienced an aggressive treatment episode at the close of life. Despite widespread support to write an AD, the benefit of written LWs remains controversial. The importance of LWs and other ADs has been studied for over two decades, but their position in clinical practice may still be vague and dependent on several issues. Sometimes the content of a LW is not applicable to the current clinical situation. (Teno et al. 1998, Teno et al. 2007, Higel et al. 2019.) The high frequency of aggressive treatments in Study IV implies a need to develop EOL care in Finland.

The site of death in both groups was a hospital in 77% of cases. This is in line with all deaths in Finland (71% hospital deaths in 2008) (Aaltonen 2015). Previous findings in the USA would have suggested smaller proportions of hospital deaths in the group with a LW (Degenholtz et al. 2004). Compared with older people´s site of death in other countries, the numbers of hospital deaths in Finland are remarkably higher (Broad et al. 2013). Death at home was very rare in Study IV (16.7% among those with a LW; 5.6% among those without a LW at baseline), which is the case overall in Finland (14.5% in 2008) (Aaltonen 2015). A significantly higher proportion of home deaths was seen among those with a LW. The small number of participants does not allow the drawing of clear conclusions; neither does the retrospective method, but one might argue that persons with a LW have been pondering matters of life and death more thoroughly than those who have not signed one. This could be a reason for another observation in Study IV: the dying process was more often short, less than a week, in the group with a LW, compared with the group without one (50% vs. 27%, respectively).

7 CONCLUSIONS

Most urban older Finns aged 75–96 feel well: they express a strong will-to-live and one third of them wish to live up to 100 years. Their WTL in years is a strong predictor of survival. They think of their future in a rational way: their wishes concerning length of life are often connected with conditional aspects of functioning, dependence and health, and they do not want to become a burden to their nearest ones.

Self-assessments can be used. Recruitment of older people into discussions about life and death is possible and easy with simple questions: How many years would you still wish to live? Do you want to live up to 100 years? Why/why not? Do you have WTL? Have you completed a LW? Older people are capable and willing to take part in discussions and decision-making concerning their own lives.

However, future scenarios require attention. The fittest share of the oldest-old will stay at their homes as long as possible. There will be more limitations in their physical functioning. Dependency on others, or other factors, may not decrease in future oldest-old cohorts.

The low-level effect of a prior LW on EOL care requires action among lay people, health-care providers and their educators. The current work suggests that it might be possible to increase wellbeing and a level of care more congruent with patient preferences. It is still unclear when these LW or EOL discussions should take place, who should initiate them and how to document them in order to more effectively influence EOL care. Currently discussions about preferences, living wills and their documentation in health files are suggested to take place early, long before the occurrence of severe diseases or disabilities.

8 CLINICAL IMPLICATIONS AND FUTURE RESEARCH

Exploring self-evident phenomena raises a number of questions. However, answers to these questions cannot be considered obvious. The results of the current work suggest new measure for clinical use: WTL. Further research is needed in enhancing self-assessments of older people, EOL discussions, performing better social policies, and exploring the death process.

Discuss the preferences: What is your WTL? Do you wish to live up to 100?

Discussing WTL and end-of-life preferences with older people can foster person-centred care. But how should one commence EOL discussions and promote ACP in clinical practice? The inquiries in the surveys for this thesis have been easy and practical for the respondents. Many of the oldest-old have a friendly relationship with death, unlike young professionals. Questions about WTL or surviving to old ages are likewise easy for physicians or nurses to convey, even in daily practice. Resilience and inner strengths are especially characteristic of the oldest-old: despite physical limitations or diseases, they may have a zest for life, and they may be happy with their health. Preconceived opinions about older patients among health-care providers may be tackled by means of educational workshops included in both undergraduate and postgraduate curricula. The effectiveness of such educational interventions should be examined in randomized controlled trials.

Documentation is mandatory, as well as good practices

To my knowledge, there is no geriatric research concerning associations between patient rationales to live extremely long, older people´s health behaviour and their willingness to be engaged in preventative actions. The future perspectives in greying societies compel us to widen research into self-care and the management of multimorbidity among older adults and the oldest-old. The wisdom of older people can be – and must be – exploited in future research, social services and health care.

Treatment plans in social and health care can easily be used for documenting preferences, personal goals and ADs, so that they can be visible in all care units. Previous research has proved that guidelines are needed for all levels of the care path. There are some good examples of this from various parts of the world.

Society needs validated measures

The association between WTL in years and the PWB scale that was used for this thesis is a topic for future research among the old and the oldest-old. Both concepts reflect the same domains of life. Future research could foster their evidence-based implementation into clinical practice, especially in primary care but also in secondary health care and policy-making. Initiatives were taken at least in France, the UK and the USA some years ago to add measures of self-reported wellbeing to assess economic performance and social progress. Economic variables are not considered as appropriate measures alone. (Steptoe 2015.)

Demand for resources in home care

The results presented in this thesis suggest an increase in number of disabled older people at their homes and later on probably in institutions as well. The levelling-off of improving functioning in later decades might be worse than expected. Previous studies have explored the future of the older population in Finland, including institutionalized citizens (Jylhä 2013). That is the best way to investigate health trends on a population level. Study III was representative of only the fittest share of older people. As such, it represents an alarm not only to those in health care but also to those who plan and construct new houses, pavements and mobility aids, and those in modern media.

From living wills to advance care planning in primary health care

Judging by previous research results and the findings in Study IV, a LW in itself does not guarantee the best treatment option. The content of a LW does not fit properly in the clinical situation at the moment. A nearing death cannot be predicted. This leads to a situation where there is no room for discussion about EOL, or the patient may feel it

offensive. Treatment decisions are made by a physician, but the patient has to comply. In acute settings there is no time to discover patient preferences properly. Instead, timely discussions should start long before the appearance of acute or severe chronic diseases. The continuity of care that many patients experience with their general practitioner or home-care nurses may be the best basis for initiating discussion (Michiels 2007, Wrede 2013, Scholten 2018). If we move from LW documents towards an ongoing process of sharing a patient´s values and goals, we can better understand what options for care the patient would probably choose later. Activity, participation, personal resources – they are among the main domains in ICF framework proposed by the WHO (2001).

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